S. HRG. 103–205

THE AGING NETWORK: LINKING OLDER AMERICANS TO HOME AND COMMUNITY-BASED CARE

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED THIRD CONGRESS

FIRST SESSION

WASHINGTON, DC

JUNE 8, 1993

Serial No. 103–9

Printed for the use of the Special Committee on Aging

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TUESDAY, JUNE 8, 1993

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

The Committee met, pursuant to notice, at 10:03 a.m. in room 562, Dirksen Senate Office Building, Hon. David Pryor (Chairman of the Committee) presiding.

Present: Senators Pryor, Cohen, Feingold, Grassley, and Craig.

Also present: Christine V. Drayton, Chief Clerk; Holly Bode, Professional Staff, Kirkley Thomas, Professional Staff; Jennifer Green, Staff Assistant; Mary Berry Gerwin, Minority Staff Director; Victoria Blatter, Professional Staff; and Katherine DeCoster, Professional Staff.

OPENING STATEMENT OF SENATOR DAVID PRYOR, CHAIRMAN

The CHAIRMAN. Good morning, ladies and gentlemen. Our meeting will come to order. We welcome all of you this morning. I have a very short statement.

I would like to announce that this morning at 11:30 the Senate will have a vote—in fact, we will have two back-to-back votes so we will have to complete all of our testimony and adjourn our meeting before that. All witnesses should be advised that 5 minutes would be the maximum for testimony, and then, of course, we would have the privilege of questioning those witnesses after that.

The Special Committee on Aging this morning is addressing the role of the aging network in long-term care. We have before us a very distinguished panel of witnesses, each of whom will attest to the vital role that this network plays in the delivery of home and community-based, long-term care services.

We are particularly pleased to have the new Assistant Secretary for Aging, Dr. Fernando Torres-Gil with us this morning. Elevation of the Commissioner on Aging to Assistant Secretary status is a substantive change and a strong message that will heighten the visibility of aging programs. With Dr. Torres-Gil at the helm, I am very confident that the Administration on Aging will fulfill its responsibilities as the primary Federal agency advocating for the elderly in America.

In 1990 the Pepper Commission identified the need for an infrastructure to support any future long-term care system. During the reauthorization of the Older Americans Act, I proposed, with sev-

eral others, a demonstration project to determine how effectively the aging network could serve as this infrastructure. Later this year, the President and Mrs. Clinton will announce their proposal for health care reform, which I hope will include a long-term care component.

While fiscal constraints continue to make it extraordinarily difficult to provide for a comprehensive long-term care program, we cannot continue to ignore the reality of the growing long-term care needs of our ever-increasing aging and disabled population. Regardless of how we, as a nation, decide to address the long-term care challenge, we now must begin to take the steps necessary for us to effectively meet this challenge. Examining possible infrastructures for the delivery of long-term care services is one way that we can accomplish this goal.

Today's hearing will highlight one alternative for the delivery of long-term care services. The OAA has developed a number of programs for persons in need of home and community-based and institutional long-term care services. In addition to providing home health care services, the OAA is the only source of Federal support for long-term care ombudsman services, which are advocacy services for residents of nursing homes and board-and-care homes. While the amount of funding devoted to home care services under OAA represents a small fraction of the amount spent for those services under Medicare and Medicaid, the services provided by the Act are available to all persons, without strict eligibility requirements.

The States have been in the forefront of finding ways to restructure their long-term care systems in order to reduce or control the cost of institutional care while expanding the availability of home and community-based care. Some State and local agencies on aging have played a substantial role in these initiatives.

Today our witnesses represent each level of the aging network, from Dr. Torres-Gil to Mrs. Frances Hicks, whose mother receives services from her local AAA in Alexandria. We look forward to hearing their testimony.

Before we call our first panel, let me yield to my distinguished colleague and vice chairman, Senator Cohen.

STATEMENT OF SENATOR WILLIAM COHEN

Senator COHEN. Thank you very much, Mr. Chairman. A couple of comments, and also a word of apology.

The Chairman several years ago headed up a task force to improve the quality of life in the U.S. Senate. I would say that he was not successful in that effort. He and I also share membership on a committee to reform Congress to make it more efficient and to make it more effective. We can use those two catchwords. But I find myself neither having a quality of life nor being efficient or effective in this particular regard.

I have to leave in a few moments to attend a Judiciary Committee hearing, which I am also required to co-chair, just having left the Government Affairs Committee on the urgent requirement to be up here. So you can see we have a number of competing types of claims upon our time, so I want to apologize particularly to

Donna Sargent, who is here from my home town of Bangor, Maine, and I'll mention just a few words about her in a moment.

Mr. Chairman, Hubert Humphrey reminded us over 15 years ago that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadow of life, the sick, the needy, and the handicapped. I think we have to keep that comment very much in mind as we await President Clinton's proposed comprehensive health care reform, because in that and part of that overhaul of our current health care system hopefully will be some components, perhaps not fully blown as such, but at least the incipient components of long-term care.

We all know that most of our people are not the beneficiaries of a long-term care policy as such—health care policy, insurance policy. Only about 2 percent have this kind of protection. Others have to rely upon the principal program Medicaid, for which they have to spend themselves into poverty. That is not a policy that we can continue any longer. It cuts across the grain, I think, of our moral sensibilities to force people to spend themselves into poverty in order to be able to afford long-term care. So we await President Clinton's proposal. We have a number of those amongst ourselves. I have one of my own. But, nonetheless, we will work toward that end and work with the Administration.

At our last long-term care hearing, we heard how an area agency on aging—an AAA of a different sort, as we say from the travel agency—but the area agency on aging in Maine helped make a tremendous difference in the life of a woman who suffered from multiple sclerosis. She was "dumped" back into her home after a stay in the hospital where her leg had been amputated. She received no discharge planning from the hospital and received no home care. When she contacted that local area agency on aging, she had no running water, she had no functioning bathroom, she was dangerously close to requiring nursing home attendants.

The AAA was able to find a small grant to allow her to have a well dug, a septic tank put in, and a bathroom installed, so that woman was able to live independently at home. This was a tremendous benefit to her as an individual. It was also a tremendous benefit to the Federal Government or to other State governments as such or agencies, because it would have been a tremendously expensive proposition for her to be forced into a nursing home.

So the local area agencies on aging furnish a whole array of services. They are in fact perhaps one of the last hopes of helping people to work their way through a bewildering array of programs. I have a chart here, and I think one of our witnesses from the Administration, Dr. Torres-Gil, will perhaps explain how he intends to reform this chart, which looks like something out of an architect's nightmare as to which programs will be available under what circumstances.

I'm sure you're going to want to address this, Dr. Torres-Gil, for the panel.

The fact is we've got to reform this system and simplify it, and we have to depend upon these area agencies on aging to help with that. Flexibility is also going to be required. A program designed to help out in Little Rock, Arkansas, will not be applicable to either

Detroit, Michigan, or to Bangor, Maine. We have to have a great deal of flexibility built into these programs.

Mr. Chairman, last week I was privileged to hold two conferences back in Maine, one on comprehensive health care, at which one of my colleagues from the House some years ago, Bill Gradison, came and testified, and he said that health care for most Americans is not a decision made in Washington, but a decision made around the kitchen table. That is precisely what is going to take place with respect to people who have to come to grips with the long-term care needs of their parents or their grandparents or, in some cases, even their children who have suffered from either a serious accident requiring this type of care or from an illness.

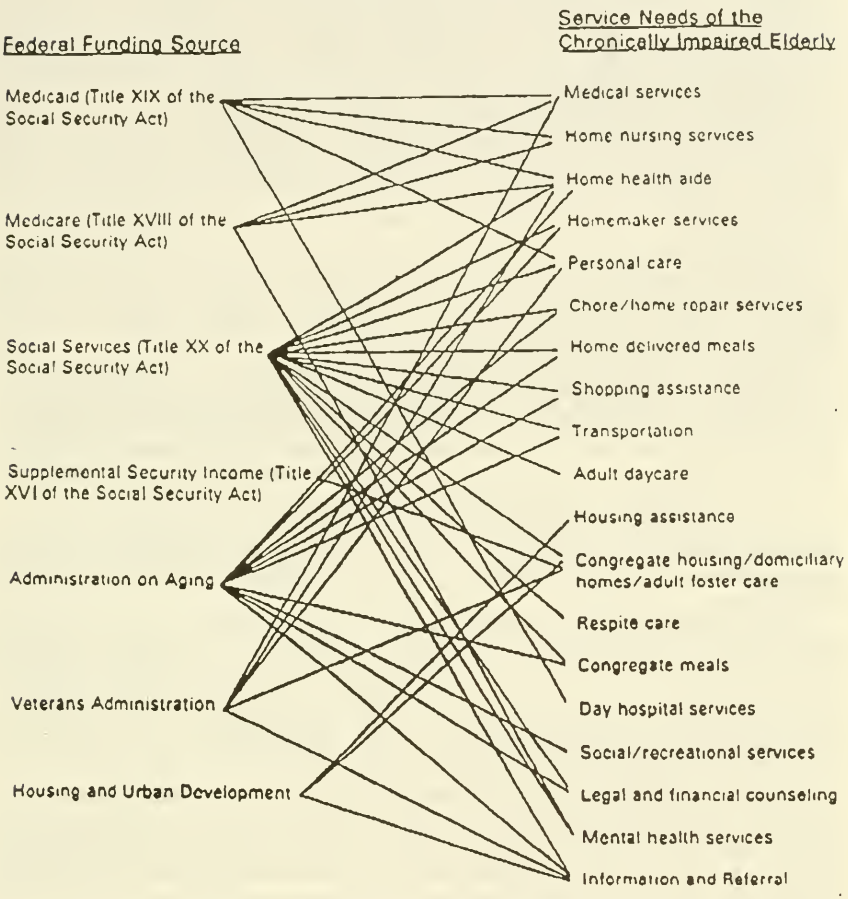
So, again, let me welcome my friend from Bangor. Donna Sargent is the Director of Health Services for the Community Health and Counseling Services in Bangor. She's a nurse, a certified nursing administrator. She has over 17 years of experience in linking older Americans to long-term care services, and we're very fortunate to have her with us today.

I again apologize. I will probably be back and forth between the Judiciary Committee and up here before the votes occur at 11:30.

Thank you, Mr. Chairman.

[The prepared statement of Senator Cohen follows:]

Major Federal Programs Funding Community Services for the Elderly



PREPARED STATEMENT OF SENATOR WILLIAM S. COHEN

Thank you, Mr. Chairman. I am pleased to be here with you today to discuss the vital role the Aging Network plays in coordinating and planning long-term care services for the nation's seven million elderly in need of assistance.

Hubert H. Humphrey reminded us over 15 years ago "that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those in the shadow of life, the sick, the needy and the handicapped." Today, as we anticipate the President's proposal on comprehensive health care reform, we must keep this wisdom in the forefront of our minds and stand ready to apply this moral test.

As we have heard many times in this committee, the lack of a national policy toward long-term care has caused too many people to fall between the cracks of Federal and State programs. Only 2% of the elderly population currently have long-term care insurance. The high costs of nursing homes and home care services quickly wipe out the life savings of uninsured families in need of care. Expenses can range from $40 to as much as $200 per day for home care, or $40,000 a year for a nursing home.

For many of these individuals, the Medicaid program, by default, becomes the primary payer of nursing home costs and, in some cases, home-care expenses, forcing families to spend themselves into poverty in order to qualify. Others who do not qualify for Medicaid must apply for State programs, for which they may also be ineligible and which are often filled to capacity.

Local Area Agencies on Aging are often the only places where individuals in the community can be provided with comprehensive assistance in locating long-term care services. While each state coordinates long-term care programs differently, most states rely in some part on the referral and coordinating role of these agencies. As Congress decides how a long-term care program can be best factored into a comprehensive health care reform package, information regarding the role these agencies play in linking older Americans to services is vital.

At our last long-term care hearing, we heard how an Area Agency on Aging in Maine made a tremendous difference in the life of a woman with Multiple Sclerosis who was "dumped" back into her home after a stay in the hospital where her leg was amputated. She got no discharge planning from the hospital, and received no home care.

When she contacted the local AAA, she had no running water or functioning bathroom and was dangerously close to entering a nursing home. The AAA was able to find a small grant to get a well dug, a septic tank put in and a bathroom installed, so that the woman, was able to live independently at home. The services provided by the Aging Network in this case made a world of difference to this vulnerable senior and allowed her to choose between a life of independence and a life spent in an expensive nursing home. In the process, it saved thousands of dollars to both the family and the government in nursing home expenses.

Local Area Agencies on Aging furnish a whole host of services and programs aimed at helping those in need. Most everyone associates AAA's with the congregate and home-delivered meals provided through the Older Americans Act, but they also supply critical information to clients and refer them to appropriate services, coordinate care programs including home health care, personal care and chore assistance, develop hospice, respite, and Adult Day Care programs; and provide seniors with a variety of advocacy services.

For too long in this country, nursing home care was seen as the only alternative for disabled or chronically-ill elderly persons whose families could not provide care or whose medical condition required skilled-nursing services. We are fortunate that this attitude is changing. The fact of the matter is that there is no one specific way to care for an individual. Each person requires a different level of care, has a different network of family and friends to assist them, and has different financial resources to support their needs.

Flexibility within care programs must be matched with flexibility in Federal and State programs designed to meet the needs of this frail population. Service delivery in a rural area differs greatly from service delivery in urban areas, and what works in Detroit, Michigan may not work in Dexter, Maine. Therefore, as we piece together a package of long-term care proposals for consideration in health care reform at the federal level, it is important that we understand the successes and failures of programs already in place in communities throughout the United States.

Mr. Chairman, just last week I had the opportunity to participate in two health care conferences in Maine, one dealing with overall health care reform and the second, sponsored by the Southern Maine Area Agency on Aging, on the services available to meet long-term care needs. At the first conference, my former House col-

league Bill Gradison observed that health care for most Americans is "not a decision made in Washington, but is a decision made around the kitchen table." This is particularly true when a family is making the difficult decision of how to care for their loved one who needs long-term care.

Today's hearing will give us a better idea of the type of long-term care programs at work on the state level and what role the Aging Network can play in delivering services—and in helping families make their long-term care decisions.

I am also extremely pleased to welcome as one of our witnesses today Donna Sargent, the Director of Health Services at Community Health and Counseling Services in Bangor, Maine, who has joined us to discuss the relationship between service providers and local Area Agencies on Aging. Community Health and Counseling Services is a not-for-profit agency that provides thousands of elderly Maine residents with critical nursing, home health aide and homemaker assistance. As a Nurse and a Certified Nursing Administrator, Ms. Sargent has had over seventeen years experience in linking older Americans to long-term care services and we are fortunate to have her with us today.

The CHAIRMAN. Senator Cohen, thank you. Just for the record's sake, Senator Cohen made reference a few moments ago to the Quality of Life Committee that I chaired. I don't know who named it the Quality of Life Committee. I always thought of it as the Quality of Work Committee so that we could produce better work in the Senate for our constituents out in the States and around the country, but, anyway, somehow it became known as the Quality of Life Committee. We have a good time, at least, talking about that. I'm afraid it's not improved.

Senator Feingold.

STATEMENT OF SENATOR RUSSELL D. FEINGOLD

Senator FEINGOLD. Thank you, Mr. Chairman, Senator Cohen. I'm pleased that this series of excellent hearings on long-term care continues in this Committee. The subject of long-term care could obviously not be much more timely, and I'm delighted that the distinguished Chair has devoted today's hearing to, in particular, the diversity of State efforts in this area.

The work of this Committee, I think, has already effectively made the case for significant long-term care reform as a part of any overall health care reform package, but this hearing today will help further validate our claim in that regard. It will also underscore the desirability of pursuing a State-based long-term care reform program in the context of a national law, allowing the States the flexibility to design and administer their own long-term care systems within overall national goals and standards. It's at the State level, in my view, that significant long-term care has been pursued, and we should continue to look at the States as laboratories of reform in this area.

I am particularly pleased that Donna McDowell, the Administrator of Wisconsin's Bureau of Aging, will be contributing to the discussion today. She's recognized as one of the Nation's foremost experts on long-term care reform, having helped to design and oversee Wisconsin's Community Options Program. This is our home and community-based long-term care program for the elderly and disabled, which I have had a number of occasions to preach about here and also in conversations directly with the First Lady, who has acknowledged Wisconsin's program in this regard in recent discussions.

Donna McDowell is also the current President of the National Association of State Units on Aging. I had the pleasure of working

with her in the 10 years that I had the chance to chair Wisconsin's State Senate Committee on Aging, and I remember well in 1984 that she was one of the two or three key people who helped advise me on creating an Alzheimer's disease program in Wisconsin, a subject that we were able to take a leadership role on. Donna was one of the principal authors of the long-term care reform package offered by the National Association of State Units on Aging, and as an administrator, her keen understanding of how long-term care systems work provide her with the insight to know what reforms are needed, what can work, and, just as importantly, what cannot work.

The reforms she helped author in Wisconsin have not only provided consumer-oriented services for the elderly and disabled—and they've been very wonderful in that regard—but I think we have demonstrated they've saved taxpayers in Wisconsin hundreds of millions of dollars just in the last 10 to 15 years. Because of these reforms, unlike most other States, Wisconsin's Medicaid nursing home bed utilization not only stopped growing, it actually dropped. During the 1980's, instead of the expected increase in the Medicaid nursing home population of about 8,000, we saw a decrease of about 7,000—a difference of 15,000 nursing home residents on Medicaid.

So we are very proud of Donna McDowell and her pioneering work on long-term care. I, along with others in the legislative branch, will be making extensive use of her experience as we reform long-term care, and I certainly hope, as the Chairman has indicated, that the Administration will do so as well.

So I look forward to her testimony today, and, again, I'm delighted to be a Member of a committee that is providing the leadership in the entire Congress on the issue of long-term care.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Feingold.

Senator Craig, glad to have you here this morning.

STATEMENT OF SENATOR LARRY CRAIG

Senator CRAIG. Thank you, Mr. Chairman. Let me also join in thanking you for holding this series of hearings on our senior community and the care they're receiving. I think it's most appropriate that we look at the coordination that goes on with the area agencies on aging and the long-term care issues that we're concerned about, especially in today's environment when this Congress is, in a very real bipartisan way, going to grapple with the whole issue of health care. We have to review these issues in cooperation with the Administration. Health care reform is a priority that's now front and center, and let us get on with dealing with it, but in the total context.

I say that because of my involvement with the senior community in my State over the years. It is obvious to me that it is not a complete program—it is confusing at times—and I think my colleague held up a chart that says that even in our best efforts, we've created some great complications resulting in holes that many of our seniors fall through.

I've been getting that firsthand from a first cousin of mine, a very favorite first cousin of mine, Carolyn Craig, who is a seniors

advocate in Idaho and who works directly with the senior community on a day-to-day basis, and just this last week when I was in Idaho, Carolyn, doing what she does so very well, called me. She ran down her favorite Senator and said, "Larry, I'm having real problems trying to get prescriptions filled for seniors, trying to keep them in their homes and keep them well cared for, and at the same time deal with the obvious dollar crunch that we're all experiencing." So I was working with her on those problems. That affects the long-term care issue.

I notice today we're going to be hearing from care givers, along with other individuals who have had a direct, hands-on experience with our area agencies on aging. I think we all ought to listen very closely to those who are at the level of having a direct relationship with our senior community and working with the programs and the spending that we have put forth. It is, in some instances, working. We're serving some, but we're not serving in the magnitude or at the level of care that I think all of us believe we ought to, especially in the field of long-term care.

So I thank you, Mr. Chairman, for these hearings. Hopefully, they'll allow us to build an informational base that will chart a course to more comprehensive and less confusing, and probably more efficient care than currently exists.

Thank you.

The CHAIRMAN. Senator Craig, thank you very much. Thank you for your good statement and comments.

[The prepared statement of Senator Craig along with the statements of Senators Richard Shelby, Alan Simpson, Conrad Burns, and Barbara Mikulski follow:]

PREPARED STATEMENT OF SENATOR CRAIG

Mr. Chairman, thank you for conducting this hearing on Area Agencies on Aging (AAA's) and the coordination of long-term care services. The issue of long-term care is very important as the Congress continues to grapple with health care reform, and I look forward to hearing from our panel of witnesses today on the role of AAA's.

It is my understanding that AAA's provide information and referral services to our elderly who are in need of long-term care. In addition, some States also use the AAA's to provide case management for those elderly who are also Medicaid eligible.

I am concerned about the duplication of services and the barriers that may be created by Federal and State laws that prevent agencies from working closely together to meet the needs of the individual in the most cost effective manner. I hear about some of these problems from someone first hand: my cousin Carolyn Craig, who is seniors advocate in Idaho. She has given me some very good insights into the problems and the benefits of different programs, some of which will likely be addressed today.

At a time when we must be fiscally conscientious, it is important that we ensure we are getting the most out of every Federal dollar. Waste due to inefficiencies must be eliminated so that our funds are used to benefit those who need to access these services. Therefore, the experiences of the States that are represented here today by our witnesses, should be useful as we work on balancing the budget and move forward on reforming our health care system.

I hope that this hearing will shed some light on where we are achieving our objectives, where we aren't, and how we can improve the system. We are all looking for ways to improve the delivery of health care services. Long-term care is an integral part of reform, and I am sure the experiences that will be related today will be helpful to us.

PREPARED STATEMENT OF SENATOR RICHARD SHELBY

Mr. Chairman, I commend you for scheduling this hearing today to discuss how the aging network provides home and community-based health care for the elderly.

We are fortunate to have a distinguished panel of witnesses with us this morning who will provide this Committee with some valuable insight into this complex problem. I also am very hopeful that this hearing will identify ways to help us control long-term health care costs when this care is provided in the home and in community-based facilities. In addition, I hope that this hearing will present some creative solutions to the special problems of individuals living in rural communities who in some instances may have fewer options available to them than individuals in urban communities.

I am very pleased that the Older Americans Act provides funding for home and community-based care programs for the elderly. These programs allow senior citizens to stay in their own homes and remain independent in their communities.

A multiplicity of services are provided such as meals on wheels, group meals, home care, adult day care, and transportation. I have seen what a difference these programs have made to the elderly in my State—seniors have avoided the high cost of long-term care in nursing homes and other institutions, and at the same time, senior citizens have been able to hold on to their dignity and independence.

The U.S. Bureau of the Census projects that by the year 2000, persons 65 and older would represent 13 percent of the population, and this percentage could climb to 21.8% by the year 2030. As our population grows older, the demand for long-term care increases. Presently, over 1.5 million Americans reside in nursing homes. This number is expected to increase to 2.2 million by the year 2000, and to 4.5 million by the year 2040. In addition, by the year 2000, 7.2 million senior citizens will need some type of long-term care assistance to help them perform daily activities to maintain their independence. This number will increase to 14.4 million by the year 2050. Based on these projections, it is obvious that the country cannot afford to house all of these senior citizens in nursing homes. Moreover, it would be undesirable to do so, since home and community-based alternatives should be more cost-effective.

All of us who have had a parent or elderly relative for whom we have provided care and support realize the importance of home and community-based care programs. The home-delivered meals or the adult day care may have been the assistance which made it possible to keep that loved-one at home. It is important that we, in the Congress, continue to support home and community-based programs. I believe that they are not only more cost-effective than other alternatives, but they also allow senior citizens to maintain active lives with dignity as they grow older.

I am anxiously awaiting the President's health care reform proposal which I hope will address this issue. I want to thank the witnesses for being with us today and I am eager to hear what you have to say.

QUESTIONS

1. Is institutionalized long-term care substantially more expensive than home and community-based care?
2. What percentage of costs for institutionalized long-term care is paid by the taxpayer?
3. Are there any data which support the belief that the elderly prefer home and community-based care to good nursing home care?
4. What limitations should be placed on the availability of home and community-based care to avoid the creation of another entitlement program which potentially could increase substantially the overall cost of health care in this country?
5. What short-term and long-term recommendations do you have for improving home and community-based care for the elderly?
6. If home and community-based care is to be a viable alternative to institutionalized care, what lead time is necessary to insure that there are sufficient, well-trained health care providers to satisfy the demand for these services?

PREPARED STATEMENT OF SENATOR ALAN K. SIMPSON

I do want to commend my friends, Senators Pryor and Cohen on holding this hearing today on the role of Area Agencies on Aging networks in the delivery of home and community-based care. Home and community-based care are the key components to any comprehensive long-term care proposal, and it is worthwhile to explore the many ways these services can be delivered at the community level.

Area Agencies on Aging provide important resources and referral services to persons who are exploring the various long-term care options available to them at the local level.

Under the Older Americans Act, the Area Agencies on Aging were developed to provide a number of programs for persons in need of home and community-based care including home-delivered meals and transportation services. Home-care serv-

ices provided under the act through the Area Agencies on Aging are available to all older persons without strict eligibility requirements. In addition, these aging agencies are the only source of Federal support for long-term care advocacy services for residents of nursing homes and boarding and care homes.

Wyoming is only one of a handful of States that has one central aging agency located in our State capitol with referral phone numbers for every county in the State. Our agency on aging works very hard to provide as many services as possible to our State's senior population. Seniors in Wyoming depend on the agency for much-needed home-delivered meals and transportation services.

In this day and age, when nursing home services have become prohibitively expensive for most persons, home and community-based care is a necessary and vital component of long-term care services. Area Agencies on Aging play an important role in providing information and referral services to communities as well as providing some of the actual home-care services.

Today's hearing is important for us in examining all of the possible infrastructures available for the delivery of long-term care services such as the Area Agencies on Aging. I want to thank Senators Pryor and Cohen for bringing this important topic to the attention of our Committee.

Prepared Statement of Senator Conrad Burns

Thank you, Mr. Chairman. Though I am unable to listen to all our witnesses here today because of another Committee hearing going on, I want to thank them for coming and assure you all that I will read the hearing proceedings with interest.

Long-term care is something with which I am truly concerned. As I've discussed in these hearings before, late last year I went out of the grandpa business real quick. I lost my Dad and my father-in-law, both within a month. Though my Dad never spent a day in the hospital until he died, long-term care was something we had to discuss among the family.

And in rural areas, long-term care services can be difficult to access. I have requested the GAO do a report on long-term care in rural areas because of some interesting figures that have come to my attention. Statistics have shown that women outlive men on the ranches in Montana. On top of this, in 1990 the average woman in Montana earned only 60 cents for every dollar earned by the average Montana male. This is alarming, especially for women who live alone. I am persuaded to think that accessing long-term care for this specific population would be difficult at best.

It is one thing when long-term care facilities are lacking due to population. And it is another when the option of home care is unrealistic because of the great distances that must be traveled. But when you factor cost into this equation, along with the lower salaries paid to women, long-term care services may be prohibitive.

We do have 11 Area Agencies on Aging in my State. And I must tell you they do a tremendous job. They serve as valuable resources for our seniors and much of the time, they are the only link to elder care services folks in Montana may have.

Last week, I held a health care conference in Missoula, Montana, attended by about 150 folks from various industries. At the end of this conference, I had everyone fill out a survey to find out where they were coming from and where they wanted the State of Montana and the Nation as a whole to go. One of the questions I asked was "Do you believe that long-term care should be considered in a major health care package or should it be explored as a separate issue in the future?"

I think the results will interest you. Almost twice as many responded that long-term care should be considered separately. The reason I think this is worth mentioning is that the folks I talk to see long-term care as an issue that deserves to be considered by itself, without bogging it down with other health care reform issues. As Senator Pryor so clearly stated, many State and local agencies have played substantial roles in restructuring their systems to reduce costs and expand access to care.

We can play a guiding role and I believe we can help in providing coverage, as the "BasiCare" bill of which I am a cosponsor does, but when it comes to deciding how best to provide these services, I think we need the advice of those who do it best and those who have been doing it successfully—folks like the Area Agencies on Aging.

Mr. Chairman, I thank you for holding this hearing today and I look forward to hearing from the State and local agencies as well as from Dr. Torres-Gil. Working together I think we can make real progress toward linking older Americans to home and community-based care.

Thank you.

PREPARED STATEMENT OF SENATOR BARBARA A. MIKULSKI

I would like to express my thanks to Chairman Pryor for holding this morning's hearing on long-term care. During your tenure as Chairman of this Committee, you have done a great deal to increase understanding about commonly misunderstood aspects of aging and for this I commend you.

Mr. Chairman, long-term care policy in this country needs to be reevaluated—and soon. Myths that have driven Americans' thinking about aging and long-term care need to be dispelled.

For the past several years, Americans have believed that children of elderly parents will take the first chance they get to dump Grandpa or Grandma at the nearest hospital or nursing home.

The myth of "granny-dumping" doesn't stand up to the facts.

A recent study from the University of Michigan revealed that 7 to 10 percent of middle-aged people gave money to their parents and a third donated time. Some of these children are taking their parents to the supermarket. Some are caring for their parents in their homes.

Regardless, the bottom line is that children are caring for their elderly parents, not abandoning them.

And what about that great myth of the last 20 years that extended families are a thing of the past. Families like those shown in popular television shows like "The Waltons" were supposed to be a dying breed because our society was constantly on the move.

60 percent of people 18 years and older live within an hour's drive of their parents. A recent survey from the National Center for Health Statistics shows that 85 percent of adults saw or spoke to their children at least 2 to 7 times a week.

People are not ignoring the responsibilities of being part of a family. They are facing up to the responsibilities and in many cases are caring for more than one generation.

The same study I referred to a moment ago also shows that 30 to 40 percent of people in their 50's with children were helping them and a third were helping parents financially or in other ways.

Two of the most explosive costs for Americans over the last decade have been college education and long-term care.

Middle-class Americans have been working their fingers to the bone so that they can write a five-figure check to their son's or daughter's college each year and then open up their checkbooks to write another five-digit check for Grandma's or Grandpa's long-term care.

For any middle-class family in that situation, there aren't enough dollars to last. Instead, Grandma may have to move in to receive care in her child's home or the son or daughter might have to skip a year of college to work and save money for tuition.

When we talk about long-term care, we are not talking simply about the aged, we are talking about families. We are talking about helping caregivers as well as those receiving care. We need to help families. Improving the long-term care system in this country directly helps people of all ages.

Mr. Chairman, older Americans need to be rewarded for wise preventive practices. Not just preventive health but preventive financing. When I was a kid, we used to say a penny saved is a penny earned.

Today, senior citizens aren't convinced that a penny saved means anything. First, because it takes thousands and thousands of saved pennies to afford 1 year of long-term care. Second, because he can look at his neighbor who took several Caribbean cruises during his lifetime and now draws Medicaid because he spent all his pennies long ago.

We need to reward older people who have saved for a rainy day. We don't need to keep giving them the wrong incentives to hide assets in order to qualify for Medicaid.

And when a long-term care parent has the drive to get out of a hospital and start therapy, he or she should have a broad continuum of services available to them to get that physical therapist to the home or wherever needed.

Instead, we have doctors scratching and clawing to get a patient a home health aide. There are often too many hassles so instead a patient gets put back in the hospital or back in a nursing home because there is nowhere else for them to go.

The incentives are all wrong. A person who takes care of him or herself should be rewarded not punished with a lack of available services.

Mr. Chairman, we can't continue this abysmal record on aging issues.

Over the last 12 years, the Social Security Administration has been trying bravely to handle more claims with fewer workers.

The White House Conference on Aging has been neglected.

The Administration on Aging programs, which my Committee oversees, has suffered from a lack of technical assistance and funding. As Secretary Shalala pointed out in her testimony before my subcommittee a little over a month ago, there are only two government networks that stand ready to respond to the needs of the elderly consumer—the Social Security Administration and the Administration on Aging (AoA). The AoA network could be used to improve our long-term care system but instead they are trying to keep their heads above water.

The network of Area Agencies on Aging (AAAs) are often the only connection between elderly citizens and their communities. But we have only begun to tap what the Area Agencies on Aging are capable of doing. These agencies can serve as individual laboratories for new ideas and new ways of providing care to senior citizens. Currently, they provide transportation, housing, nutrition, and preventive medicine services.

These are the services that are the heart and soul of long-term care. Long-term care is not just medical services. It must be a broad continuum of services available to senior citizens.

Area Agencies on Aging are already providing the home and community-based services that many policymakers are talking about expanding. Poll after poll shows that Americans want home and community-based care. Government needs to respond to the people. They do not want to be placed in institutions simply because there are no alternatives.

These agencies can serve as incubators for new ideas and methods for delivering long-term care. But we must support them. They cannot serve in that role when their budgets are shrinking.

A shrinking budget also should not be a hurdle for the National Institute on Aging (NIA) but it is. the Institute does valuable research on trying to reduce the prevalence of illness and disability among the elderly. This research not only improves the quality of life for seniors, but it also produces more cost-effective medical practices. And quality of life and cost-effectiveness should be the criteria for any long-term care research as we look towards the next century. Now is not the time to be reducing NIA's budget.

The actions of the last 12 years lead me to believe that many government leaders aren't aware of what's coming down the tracks.

The CHAIRMAN. Let's call our first panel this morning: Dr. Fernando Torres-Gil, the Assistant Secretary for Aging, Administration on Aging, U.S. Department of Health and Human Services. Dr. Torres-Gil is accompanied by someone who is no stranger, Portia Mittelman, who is the Principal Deputy Assistant Secretary for Aging, and the reason that Portia is no stranger here is she was the former staff director of this Committee.

Portia, we're proud to see you here today.

Mr. Edwin Walker, the Director of the State and Community-Based Programs, is accompanying Dr. Torres-Gil, as well. We look forward to your statement.

STATEMENT OF HON. FERNANDO M. TORRES-GIL, Ph.D., ASSISTANT SECRETARY FOR AGING, ADMINISTRATION ON AGING, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC, ACCOMPANIED BY PORTIA MITTELMAN, PRINCIPAL DEPUTY ASSISTANT SECRETARY FOR AGING, AND EDWIN WALKER, DIRECTOR OF STATE AND COMMUNITY-BASED PROGRAMS

Mr. TORRES-GIL. Thank you very much, Senator Pryor, Senator Feingold, and Senator Craig. Thank you for allowing us the time to be here to participate in this very important hearing.

This is my first testimony before the Senate, and I'm honored that it's before you, Senator Pryor, and the Members of the Senate Special Committee on Aging. You all have played a tremendous leadership role over the years, and I, having been involved in aging

and advocacy for many of those years, have always looked to you and this Committee for support as well as leadership and vision.

As you've so rightly stated, I'm pleased to have Ms. Mittelman with me as a principal deputy and Mr. Walker, who heads up our State and community programs. I'd like to also just mention that we have just—I'm able to now announce that our second deputy, Mr. Bill Benson, will also be joining us. He's back here.

Senator PRYOR. Certainly no stranger here.

Mr. TORRES-GIL. Yes. That finally got squared away, and we thank you, sir, for all your help.

Let me just say at the outset that I will certainly introduce my testimony for the record, and so I'll just make some relatively brief comments and address some of the issues that have been made here.

Today you'll hear from other witnesses about the tremendous efforts at the State and local level to promote long-term care. I think if there's good news, it's the fact that there's now a recognition—almost a consensus—both in the public and the Department of Health and Human Services, as well as among the President, Mrs. Clinton, and Secretary Shalala, that long-term care is one of the most important issues we must address and resolve and, most importantly, that we should focus especially on home and community-based long-term care.

My position as Assistant Secretary for Aging, which is a new one, thanks to the Senate and the House and the President, will allow me to move on a two-fold mission—one, to address the needs of today's older population and their families and to build on the strengths of the aging network. It's important to note that there are only two networks in the country that have proven themselves to serve older persons and other populations effectively—one, the Social Security district offices and their varied programs; the other, the Older Americans Act and the system of State and local area agencies on aging. That is an important network that must be used and built upon.

The second part of my mission is to look at tomorrow, to look at the future, to begin to prepare us for the future aging of what will be twice as many senior citizens in this country, and to that extent, we will be looking at the growing numbers and how we in the Federal Government should respond to older persons at the turn of the century and to the issues of women, minorities, and other populations.

Long-term care is both an issue for today and for tomorrow, and I think we should clarify at the beginning what long-term care is, or at least our definition. At least, long-term care ideally should be a continuum of care that provides families and individuals the choices to draw on institutional care, whether hospitals, nursing homes, hospices, as well as home and community-based care, and that that continuum should also ideally include transportation, housing, rehabilitation, and other social and supportive services.

The fact at the moment is that we don't have that continuum, and as Senator Cohen rightly pointed out, what is available is a hodge-podge of services, regulations, and programs that is very difficult to understand and access. I believe, however, we are now moving in the right direction. Thanks to Senator Pryor and others,

the Older Americans Act now requires us to institute a number of mandates that I believe will help us to put together pieces of that continuum.

In addition, as I mentioned earlier, the President, Mrs. Clinton, Secretary Shalala are committed to this concept, and we can fully expect that the health reform package will move us in that direction and include important pieces, and I can certainly address what those might be, if you wish.

But let me talk about the Department of Health and Human Services and my Secretary, Donna Shalala. When I came on board, she asked all of us to work on cross-cutting initiatives that, for the first time, would require those of us that head up the main operating divisions of the department to work together. As common sense as that might sound, in previous administrations, including the Carter Administration, where I also worked in HHS, HCFA—the Health Care Financing Administration—the Public Health Service, the Social Security Administration, the Administration for Children and Families, and the Administration on Aging did not work together. They worked independently.

Secretary Shalala and I feel that if we're going to move toward this continuum of home and community-based care, if we're going to address that complexity that Senator Cohen laid out to us, we must begin to bring together at the table HCFA, PHA, SSA, ACF as well as the Administration on Aging. To that extent, I am pleased to tell you that Secretary Shalala has instructed me as well as my colleagues, such as David Ellwood, Planning and Evaluation, Bruce Vladek, Phil Lee, and others, to sit together and develop a working group that will begin to answer the question, how can we as a department move home and community-based care, and how can AOA be a key player in moving on those initiatives?

There are many issues that we're going to have to address, and we're going to begin to look at them now and, by this summer, have a more definitive plan, as well as announce this effort. For example, what should be in-home and community-based care? How can we give families a choice? How do we integrate the various regulations and programs among those operating divisions that heretofore had been developed independent of each other into that continuum?

For example, HCFA is moving on providing greater flexibility for States to involve and use Medicaid waivers to provide home and community-based care. Bruce Vladek from HCFA and I are talking about an initiative to simplify the forms, little things such as having bold print, putting them in regular English so that seniors and their families can at least understand what it is they're eligible for. The Social Security Administration and its critical programs in disability insurance and the Supplemental Security Income program are a key aspect of long-term care, because they pay for many of those services. Certainly, the Public Health Service and their invaluable research in Alzheimer's and dementia and other areas has to be part of our efforts in that area. Even the Administration for Children and Families and the tremendous services it provides for women and children and single households has to be part of that continuum, so we have to look at how we're going to involve them.

Another critical area in our efforts is how do we enhance the capacity of the aging network to begin to build that system when we begin to get the resources, as I'm confident that we will? I would say at the moment that the aging network is not fully able to take advantage of whatever might come down the road in the next year or so, but by providing technical assistance, by providing capacity building projects, I believe that we can work with them and certainly build on the tremendous successes that the States have instituted.

To that extent, the Administration on Aging is involved in a very important long-term care program that will help answer the question: how can we assist them with that capacity building?

In conclusion, Senators, I think we're now moving in the right direction. We are looking forward to working with you. We have much work to do, but I'm confident that we're now going down the right road.

Thank you, sir.

[The prepared statement of Mr. Torres-Gil follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary
Administration on Aging

Washington, D.C. 20201

Remarks of

Fernando M. Torres-Gil
Assistant Secretary for Aging

Mr. Chairman, it is a special honor to appear before you and this distinguished Committee today in my first official Senate appearance as Assistant Secretary for Aging. The accomplishments that you and your colleagues on this Committee have achieved during the past 30 years have been critical to the health, well-being and security of our Nation's elderly. I would like to take this opportunity to thank you for your courageous leadership in both the Senate and throughout the Nation on behalf of our 37 million senior citizens and their families. I would also like to personally thank you for the support and encouragement you have given me since I was designated for this position by the President and Secretary Shalala months ago. Now that I am finally confirmed, I look forward to working closely with you and the rest of the Committee in the months and years ahead. I feel very fortunate to have Portia Mittelman by my side as my Principal Deputy Assistant Secretary, and I know you will agree that your loss is definitely my gain.

The focus of today's hearing "The Aging Network and Long Term Care" is an issue that strikes at the very heart and soul of this new position, and what I consider to be a major part of my overall mission within the Department of Health and Human Services (HHS) for the next several years. As you know, Secretary Shalala, in one of her first official acts, with the full support of the President, elevated the position of Commissioner of the Administration on Aging (AoA) to Assistant Secretary.

While I am fully aware that by statute I am still the Commissioner, I hold the dual position of Assistant Secretary within the Department of Health and Human Services. This allows me to be on the front lines with my colleagues in the Department, helping the Secretary make key decisions and bringing aging issues to all relevant tables of discussion. This elevation is the result of over two decades of Congressional interest, which includes your own legislative initiative, Mr. Chairman, the fulfillment of a Congressional mandate and also the result of the President's commitment that the leader of the Administration on Aging be the chief advocate and spokesperson for our Nation's elderly. Mr. Chairman, I view my role on an even larger scale -- as a vehicle by which I, and my staff, can "gerontologize" the rest of the Department and the Federal government. I see this new position as a means to integrate our aging concerns and interests into every facet of government, and by working together, help chart the course for the direction that aging policy will take us in the 21st century.

Until now there has not been a focal point for across-the-board aging issues in the Federal government. It is my hope, Mr. Chairman, that with your assistance, I can use this position to be that focal point, and to refine the present role of the Administration on Aging as well as positioning the agency to take the lead in preparing the country for the dramatic demographic changes that will occur at the turn of the century. By the year 2030, we will have doubled our aging population, and the retirement of the baby boomers will be in full swing. This rapid aging of our population will only exacerbate the need for a long term care plan, and it underscores the importance of planning for our future. It is imperative that we re-focus on the needs and capabilities of our elderly, and the importance of enhancing their roles within our families, our communities and throughout our society. The contributions that Older Americans provide are some of our Nation's most cherished resources.

My mission as Assistant Secretary for Aging is a two-fold one. The first is to respond to the very real needs of the elderly of today, and the second is to prepare for the next generation of elders and those who will follow them.

Having said that, I want to spend a little time talking about the needs of today's elderly and how the Federal government responds to those needs. Clearly, financial security is one need, and access to basic social human services, such as nutrition, transportation and other supportive services is another. There are currently two main types of highly successful Federal social programs for older Americans. The first is Social Security. More than one third of the aged are kept out of poverty by their Social Security benefits. More than 9 out of 10 elderly citizens receive Social Security benefits and Social Security is the the major source of income for almost 60% of aged beneficiaries.

The second type of programs, of course, are those authorized under the Older Americans Act. One of the specific missions of the Administration on Aging has been to administer the majority of the programs under the Older Americans Act. As this Act nears its 28th anniversary, it has created and nurtured a very sophisticated system of service delivery to millions of senior citizens. The beauty of the Older Americans Act is that it gives seniors tremendous options and choices as to how they might live their lives. Having those choices can often mean the difference between independence and institutionalization, or even life and death.

Services offered under the Older Americans Act provide hot home-delivered meals provided to rural communities by volunteers. They help develop health and diet education and promotion brochures for senior center programs in urban communities. They provide weekly or daily transportation services to seniors who cannot get to the store or the doctor on their own. In all these cases and more, the delivery of these critical services is carried out by a very active, energetic aging network, which by my expanded definition, goes beyond the very important State and area agencies on aging and service providers.

This network also includes a myriad of other non-traditional aging organizations such as private industry, hospitals, health insurance companies, universities, philanthropic or religious organizations, environmental groups, special aging populations, friends, volunteers and even seniors, who are also the consumers of these services. Naturally, it also includes family members who serve as informal caregivers and who play a key role in providing these services. This network has been poised to fill the void when other services have proven inadequate, and in many cases, has been filling that void for many years.

Despite severe budget constraints, chis aging network has been an effective base for building that comprehensive system of social, health and supportive services for our seniors, and in effect, has been laying a foundation for long term care. In that regard, the most recent amendments to the Older Americans Act convey several significant messages. Congress very astutely sought to reaffirm the core services of the Act -- the greater emphasis on services to minorities; the protection of the rights of the elderly; the important emphasis on health promotion and healthy lifestyles; the importance of community-based services for the frail elderly -- all of these and more -- relate in some way to the overall long term care of our senior citizens.

At a hearing earlier this year before the Senate Labor and Human Resources Subcommittee on Aging, there was discussion of what the phrase "long term care" really means. To many, it conjures up an image of a frail elderly person in a nursing home staring vacantly into space. But to the Administration on Aging, and the aging network, it is the continuum of life and of care for our loved ones which allows them to live their lives in their homes and communities among their family members and friends. It is the continuum that provides vital choices to people of all ages. This continuum must also include housing, transportation and other social services and the aging network, through its hundreds of innovative programs, has been offering care services for many years, and has the capacity to provide more, with a little help and support.

The Administration on Aging is now in an important position to be a catalyst -- to play a leading role -- in developing a solid, realistic long term care plan for our future generations. It is a golden opportunity for AoA, Mr. Chairman, to build on our vision for the future, and that is why I have made the development of a long term care plan one of my principal strategic initiatives during this Administration.

Prior to being confirmed, I was asked to serve on the President's Long Term Care Task Force, and I had several opportunities to share my thoughts with the President and with his key advisors. Since my confirmation, the Secretary has been very supportive of my efforts to forge partnerships with my colleagues in the Department of Health and Human Services to develop a collaborative plan of action around long term care. As a result of these new developing alliances, we are presently considering the formation of a long term care working group within the Department that will develop a longer term strategic plan that brings together the Social Security Administration (SSA), the Health Care Finance Administration (HCFA), the Public

Health Service (PHS), the Administration for Children and Families (ACF) in tandem with the Administration on Aging to promote the development of home and community based long term care.

Historically, we have evolved a set of long term care policies and programs that are complex, fragmented and difficult for the consumer to understand. In the Department of Health and Human Services, we have programs that each provide different pieces of long term care -- in SSA, in HCFA, in PHS, in ACF, and in AoA.

The Secretary has instructed us to develop cross-cutting initiatives that simplify and bring to bear the resources of the Department of Health and Human Services on pressing problems. Long term care lends itself to a cross-cutting approach as the Department develops a strategic plan for home and community-based long term care. The Administration on Aging will play an important role alongside SSA, HCFA, PHS and ACF.

What the Administration on Aging has to contribute is the following: our network that is based at the local and State level and draws from local and State experiences; our long historical experience in delivering social and community-based services that are user friendly to seniors in ways they know and understand; our experience with social and community-based services that we feel should be the basis of long term care; our use of discretionary funds that has been a catalyst in testing innovative approaches, such as the well-regarded On Lok Program in San Francisco. My hope is that as I share the expertise of the aging network with this working group, what will emerge is a home and community-based long term care plan, built on a social model rather than an institutional format.

The needs of our seniors are changing, and we must make the appropriate changes to accommodate those needs. The definition of the family has changed; people have different views on what they want to do in their later years -- some are beginning second or third careers. The role of women in our society and in our families has changed in the last several decades -- women are living longer, working more and often raising families alone, or serving as primary caregivers to both children and older adults. The changing role of women is a critical component of any long term care plan and will also be addressed by our strategic initiatives. We need to re-examine these needs and prepare for them in an appropriate way.

This re-evaluation process is the foundation of the second aspect of my mission as Assistant Secretary for Aging, which as I indicated earlier is to respond to the needs of the elderly of today, and to prepare for the elderly of tomorrow. One of the Secretary's first directives to me was to develop a blueprint for the Nation's future retirees, which of course, includes all of us. I take this mandate very seriously, and I have already begun a plan of action to meet the Secretary's challenge. A major component of this blueprint will be to highlight and further build upon the strengths of the aging network, but to also anticipate the future and be able to provide the network with the tools they will need to carry out their mission. Further, the plan I am developing will survey all Cabinet agencies that have an impact on individuals as they grow older, from services provided by the Departments of Labor, Treasury and Housing and Urban Development, to the various operating divisions of HHS, in an attempt to reveal how best to coordinate these disparate programs.

There are many questions that need to be answered. Are we as a Nation ready for the retirement of the baby boomers? How can we better coordinate services and increase efficiency? How do we meet the needs of the disabled and the chronically ill? How do we handle the special needs of the over-85 and the under-60? How do we target long term care to special populations such as minorities, women, rural and urban elderly? How will we assist women and caretakers to care for the disabled of all ages? How will our workforce be affected? And finally, is our Nation's economy ready for this dramatic surge in our senior population?

I hope to be able to address these questions in my blueprint, Mr. Chairman, and I look to you and your colleagues for guidance and support. I see this plan as the legacy of this Administration, and the importance the Secretary has placed on its development bears witness to the absolutely essential nature of this assignment.

President Clinton, in a White House ceremony last month commemorating Older Americans Month, reaffirmed his commitment to keeping faith with our Nation's elderly, their families and to future generations. I stand by his commitment and will continue to work hard to accomplish the tasks that he and the Secretary have identified for me. I will also continue to promote the aging network and encourage it to continue its excellent work.

I would be happy to respond to any questions you might have.

The CHAIRMAN. Dr. Torres-Gil, thank you. We are very honored that you would choose this Committee to make your first appearance and give your first testimony. We feel that there will be many other opportunities for you to come before this Committee.

Last week I understand that some of our staff people met with some of your staff people. I think Senator Cohen held his chart up a few moments ago, and really it looks like the Super Collider there, or plans for it. I'm going to ask this question in behalf of Senator Cohen, because he wanted to talk about this morning. This complex system that we have here shows the various sources of Federal funding for community services for the elderly. Dr. Torres-Gil, you stated that Secretary Shalala has instructed you to develop new initiatives to simplify those programs.

Now, has this just grown up hodge-podge over the years, and have we just sort of neglected to look at the tremendous complexity of all of these programs, or has this grown up according to some strategy or overall plan? What happened to us, and what can we do about it?

Mr. TORRES-GIL. I guess to be kind, Senator, I can say that in the last 25 years we have kind of made it up as we went along. The reality, sir, is that there was never a comprehensive long-term care strategy that guided the development of the Medicaid/Medicare Program, the housing and transportation and other social services, like title XX, SSI, DI, and the Older Americans Act. For whatever reason, all these programs were developed independently of each other, including their laws and their regulations, eligibility and funding criteria, and each over the years has begun to add on certain bits of long-term care. Even the Rehabilitation Act of 1973 and the more recent Americans with Disabilities Act is now moving us in that direction, but it, too, is evolving independently. So it just kind of happened that way.

What to do about it? We're going to look at that carefully, but what I'd like to do is ask Mr. Walker, who's going to be heavily involved in that area, to also share some of the principles by which we hope to finally grapple with this non-system.

Mr. Walker.

Mr. WALKER. Yes. I would cite two specific things with regard to what we believe will occur. One is that the Vice President's initiative with regard to reinventing government is looking at a broad array of issues related to making government more efficient, more effective, streamlining it, making it more user- or customer-friendly. Certainly, when you look at that chart, you see the complexity of the chart, so it's an attempt to review what can be done at the Federal level, and we do believe it needs to begin at the Federal level, because States have been grappling with how to address the maze of funding streams.

The second area where this is being addressed is within the health care reform effort. The task force did look at the complexity of funding streams, the variety of funding streams, and charted out options with regard to how could some of these be consolidated, how do you make it easier to administer such a program. So I would say the answer is more and better coordination.

The CHAIRMAN. Senator Craig is going to have to leave us here. By the way, we have a lot of committees meeting this morning and

a lot of activity going on and around on Capitol Hill, relative to not only health care, but deficit reduction——

Mr. TORRES-GIL. All very important issues, sir.

The CHAIRMAN. So there's a lot of things happening, and they're very important issues to your job, I might say, and to the future of your jobs.

Mr. TORRES-GIL. Yes, sir.

The CHAIRMAN. Let me at this moment, if I might, yield to my friend, Senator Feingold.

Senator FEINGOLD. Thank you, Mr. Chairman.

Doctor, given the interest that many of us on this Committee have on the long-term care issue and its relationship to the overall health care reform package, and without getting into specifics—I realize you can't go too far with that—what can you tell us about the long-term care reform being included in the President's proposal? You mentioned that you might be able to address that.

Mr. TORRES-GIL. I've been in a number of meetings with certainly the Secretary, the President, Mrs. Clinton and the health care leaders, such as Ira Magaziner and Judy Feder. As you can well guess, the real issue for the task force is the cost and how much long-term care and how quickly can we begin to move on it. At least as of yesterday, Senator, the expectation is that we'll have the following elements in the package.

How much and what it's going to cost is still to be sorted out. Certainly, some kind of prescription drug coverage, which, as you all know, is one of the biggest out-of-pocket expenses for older persons and their families. The second is to try to ease the burden of those who have a relative or spouse in a nursing home and have to spend down, so serious attention is being given to easing the asset requirements so that a member in the community can keep more of their assets and still have someone qualify in the Medicaid program. We expect that there's going to be some additional home care in this package. Whether it's a block grant, whether it's just a pass-through program is still to be worked out. Certainly, the plan will require additional flexibility so States don't have to go through the extraordinarily torturous process to get the waiver for expanding home and community-base systems.

So I would say, sir, at this point those four elements, but there's a fifth I want to mention, because I know it concerns older persons. Medicare will be left alone. Medicare will not be phased into an initial health care reform program. I say that, sir, because if we're going to move on long-term care, we need to assure the elderly that what they do know that works—in this case, the Medicare program, with all its imperfections—will be left alone until this new system has proven itself, although there will be options for seniors, if they wish, to move to a health alliance type of system. So this is our basis.

The last thing I'll just mention is that we hope in the package there will be a phase-in that will kind of give us directions over "X" number of years to build on that system.

And, lastly, whatever may or may not be in the health reform package, Senator Feingold, I need to assure you what my superiors have assured me, that we're going to move toward long-term care. It will not be all in the health reform package. We're going to move

on it equally as well in the Department of Health and Human Services. That's why we're going to start within.

So it's going to be kind of a two-prong effort, whatever occurs in the health reform package—and there will be some good beginnings—alongside what we're going to do in the Department of Health and Human Services, and I think together will move us in the next couple of years toward that system.

Senator FEINGOLD. Thank you, Doctor. I take your remarks to mean that the Administration on Aging has a good opportunity, then, to meet with the task force members?

Mr. TORRES-GIL. Yes.

Senator FEINGOLD. And as you go through that, I would urge you to do whatever you can to put the issue of home-based care and community-based care at the very top of the list. I don't want to take anything away from issues such as prescription drugs and the spend-down problem. These are problems that I have worked with. The Chairman has been the leader on that. But indications that I felt were coming from the First Lady and the Administration were a significant initial commitment to the home care. I heard figures that I thought suggested a substantial commitment, not just a slow phase-in, and I urge you to do everything you can.

I believe it's essential to reduce the deficit. I believe it's something that cannot wait and needs to be part and parcel of any serious health care reform. So I urge you on in your urging on of the——

Mr. TORRES-GIL. Thank you. And let me, if I may, add, Senator Feingold—I don't want to pick and choose priorities, but home care is right up there. Let me just add, the Secretary and I met with the disability groups a few weeks ago. Highest on their list was home-based care. I should tell you there's also a consensus among us that whatever that system is, it will be applicable for groups of all ages and that home care has to be perhaps one of the most important elements.

Just one other point. AOA is now in a unique position to be an equal player with HCFA and PHS and SSA and the others precisely because the Secretary and the President have elevated that position. So to the extent I can urge people on, I certainly will, and I know that the President and Mrs. Clinton and the Secretary share your concern as well.

Senator FEINGOLD. Mr. Chairman, I'm mindful of the time limits. I have one more question. I want to have a chance for all the people——

The CHAIRMAN. Surely; Go right ahead. [Laughter.]

Senator FEINGOLD. One other question just before we leave the other point on home care. In terms of selling the health care plan to the American people, this is going to be a tough task. Everybody knows we need health care reform. I believe that the home care benefit will be one of the true points that all Americans, regardless of economic status, will understand and will see as a tremendous advantage of health care reform, and that is another more pragmatic reason why this needs to be a leading feature of the plan.

As I indicated in my opening statement, and as this whole hearing suggests, there will be an issue about what role the States will play in any particular reform, whether we're going to have a Fed-

eral program or whether it's going to be a Federal law that allows State flexibility. What are your thoughts about making the long-term care system that comes out of the national plan a State-based program and allowing different States the freedom to administer programs in their own way, within, obviously, certain national rules and standards?

Mr. TORRES-GIL. I personally favor it, sir, and I would use the example of my own State of California. In California years back, AOA funded the ON LOK project, which has been perhaps one of the most successful home and community-based programs. Initially, it began with Chinese elderly; now it serves all elderly in San Francisco. With HCFA, we are now funding 10 replication projects across many different States.

The bottom line is that we need to build a system from the bottom up. I don't think any of us feels that the Government can now do huge bureaucratic programs. The reality is that in the last 10 to 15 years, it's the States that have led the drive toward different parts of long-term care. They've experimented, they've learned from trial and error, and we need to build whatever it is we're going to do on those experiences and allow them the flexibility to come up with diverse variations of that continuum. The health care plan in fact is going to build on and relies on that principle of giving States flexibility.

So I certainly concur with you, and that is our basic principle.

Mr. Walker, anything else you might want to add on that?

He's in charge of that, to make sure it happens.

Mr. WALKER. I would just add that one reason that we are conducting this survey or are planning to conduct this survey of the States is to in fact see how the States have implemented various components of long-term care so that we can highlight the best practices and better shore up, if you will, that infrastructure so that it will be ready across the Nation to handle whatever long-term care comes through the long-term care or health care reform effort.

Senator FEINGOLD. I appreciate that answer. I make a lot of comments about Wisconsin's program, but I recognize that there are 49 other States, and some of them have done tremendous things as well. In fact, your example of ON LOK is a wonderful one. I happened to have the opportunity to tour the ON LOK Program in San Francisco a number of years ago and was inspired and very moved by the sensitivity to ethnic differences and to cultural differences and the ability of that program, as you say, from the ground up, to begin to make serious reform, and that has had an impact in Wisconsin as well. So I appreciate that answer very much.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Feingold.

One of the elements of President Clinton's argument on tying the deficit to health care is the interrelationship of the two and the fact that the deficit today, to a very large extent, has been caused by the explosion in health care costs. We're going to be debating a lot of that in the coming weeks ahead around here in the Finance Committee and the Aging Committee and on the floor of this Senate.

One of the questions that you can ask an audience that is quizzing you about health care reform, asking questions such as "Are my rates going to go up? Am I going to have the choice of my own physician?" is: What happens if we do nothing?—and that applies to the deficit issue, it applies to the health care issue.

I'm going to ask you that question right now. What happens in long-term care if we do nothing and continue this thing to go as it has in the past?

Mr. TORRES-GIL. If we do nothing, Senator Pryor, the need increases, the demand increases, the costs escalate, and we'll have a system that gives us the worst of all worlds. What it will ultimately do is bankrupt Medicaid, make Medicare inadequate, because those two systems have relied on the most expensive, the most impersonal, the most inefficient part of that long-term care continuum. I would say to you we cannot afford to wait to begin to establish that home and community-based side to build the capacity of the aging networks and nonprofit and other community-based organizations to start delivering those services. If we do nothing, the problem gets worse.

I might add, sir, you talk about the deficit and the economic stimulus package and other issues. I just want to add parenthetically that I see all that as part of aging policy. My job is to be the Department's chief spokesperson on aging policy. If we don't do anything about the deficit, for example, it will make the quality of life, if I may use that term, worse for tomorrow's retirees and older Americans.

So we have in aging and in AOA and in long-term care a great deal at stake in your success, the Senate's and Congress' success, in dealing with that deficit. Because if we don't deal with it, we will not have the fiscal resources to begin to build that continuum of long-term care.

The CHAIRMAN. Well, I want to thank you.

Senator Feingold, do you have any further questions?

Mr. TORRES-GIL. If I may, Senator Pryor, I just wanted to ask——

The CHAIRMAN. I was going to ask Portia Mittelman if she wanted to make any final remarks here. We are very, very proud to have you and very pleased that you made your announcement about our friend, Bill Benson, this morning.

Portia.

Ms. MITTELMAN. Thank you, Senator. You always had the notion of putting me on the spot when I didn't want to be. I did want to just add one other initiative that we at AOA are very pleased to be moving forward on. It comes from a directive from Secretary Shalala, and it deals with older women and the special needs and the special pulls and tugs that older women have when you're talking about this whole system of long-term care. We would like to announce that later this fall, in September, AOA is sponsoring a conference along with the National Eldercare Institute of Older Women that will look at a number of these issues, and we ask for your support as we move forward with our initiative on that area.

The CHAIRMAN. Portia, we want to thank you and want to also ask Mr. Walker if he has a final comment.

Any clean-up?

Mr. WALKER. I would just like to thank you for this opportunity.

The CHAIRMAN. Let me also take this time to announce that Portia's successor in her job as staff director of the Committee, is Theresa Forster who will join us in mid-June. Some 14 or 15 years ago, Theresa became an employee of the Committee on Aging, where she became chief clerk. She ultimately came to my personal office staff, and has most recently been associated with an organization that has been involved in long-term care. She will bring a great deal of expertise to the staff directorship.

We're very proud to have Portia here, honored to have you here, Mr. Walker, and certainly honored to have, Dr. Torres-Gil, in your first appearance before a Senate Committee. We thank you, and we'll look forward to many more.

Mr. TORRES-GIL. Thank you, sir.

The CHAIRMAN. Thank you very much.

We'll call our second panel now, please. I'm pleased to welcome Donna McDowell, who is Director of the Wisconsin Bureau of Aging. She will be followed by Jim Wilson, the Administrator of the Senior and Disabled Services Division from the State of Oregon. They each administer very well-respected State long-term care programs that utilize the aging network in very different ways. We look forward to exploring those different ways this morning as they give their testimony and answer our questions.

Ms. McDowell, we will call on you first. I might ask Senator Feingold if he has any comments or any opening remarks before you begin your testimony. I'm sure you go back years together.

Senator FEINGOLD. If I got started telling you all the good things about Donna McDowell, it would take the rest of the time, so I will decline the opportunity.

The CHAIRMAN. Thank you.

Ms. McDowell.

STATEMENT OF DONNA McDOWELL, DIRECTOR, BUREAU ON AGING, WISCONSIN DEPARTMENT OF HEALTH AND SOCIAL SERVICES, MADISON, WI

Ms. MCDOWELL. Mr. Chairman, distinguished Members of the Senate Special Committee on Aging, I am Donna McDowell, Director of the Wisconsin Bureau on Aging, and currently serving as President of the National Association of State Units on Aging. I bring greetings from home to our two respected Senators.

I'm glad that Senator Russ Feingold is here, and I have to say, Senator, that those extremely generous opening remarks about me were more reward than I expected to get for slogging all those years in the bureaucracy, and they will carry me for another decade. Thank you very much. [Laughter.]

The CHAIRMAN. Let me add that Senator Kohl informed us this morning that he was going to be in a meeting of the Judiciary Committee. He was going to try to drop by, but he did not know what the prospects would be, but he does express his apologies.

Ms. MCDOWELL. Thank you. I appreciate that.

The CHAIRMAN. You're fortunate to have two Members of this Committee from the State of Wisconsin.

Ms. MCDOWELL. Very fortunate when you're the director of the Bureau on Aging, yes.

As certainly both of you Senators know, the aging network has long recognized that reform of long-term care is a central issue for older people in all of our States and communities. In the past 15 years, States have initiated efforts to deliver long-term care in home and community settings, and many States have fully implemented statewide systems of community-based care, and most have at least the infrastructure of a delivery system in place.

The role of the State aging network from the beginning has been leadership in driving the policy debate toward a more consumer-centered view of long-term care. We have been the principal architects of long-term care reform at the State level, working to assure that the views and preferences of older people and younger persons with disabilities were systematically incorporated into the design of new long-term care programs, and we're pleased and hopeful that the new Assistant Secretary of Aging will exert the same influence here in Washington.

The Wisconsin Community Options Program is one very good example of the success of State efforts for reform. In 1982 in a bipartisan effort, the State embarked on a restructuring of long-term care which had three critical characteristics. First, a moratorium was placed on the construction or expansion of nursing homes to contain Medicaid costs. Second, new long-term care resources were directed exclusively at a carefully designed consumer-centered model of home care, called Community Options, administered by 72 counties. The target population of beneficiaries was carefully defined to limit benefits to those persons of any age who would otherwise qualify for institutional care.

Like most other State programs, the Wisconsin Community Options Program relies on case management, and that's where that incredible looking maze of programs gets sorted out. It's really at the level of the case manager and the consumer. A skilled social worker teamed with a nurse visits the older person to assess what basic daily activities the person can still manage and what functions she needs help with. The case manager also assesses the environment in which the person has chosen to live to see what home modifications or equipment can increase the person's safety and self-sufficiency. The assessment also identifies family and friends who are currently helping out or who could be enlisted to give help, and, most importantly, the assessment determines what the older person's own personal aspirations and preferences are to establish the goals of the program for the individual. The case manager's job is to mobilize/authorize payment for the supports that will realize the consumer's goals.

Those of us who have designed and delivered services to older people have learned that the reform of long-term care means moving away from a medical-orientation of professional diagnosis and medical procedures to focus on maintaining the individual's ability to function as much as possible in familiar settings in ways that keep him or her confident and comfortable. State units like Wisconsin's have been advocates, planners, and administrators who are reshaping the idea and operation of long-term care.

To accomplish this mission, Wisconsin has made very explicit policy decisions that are necessary to reinforce this consumer responsiveness. For example, Wisconsin will use public funds to sup-

port any service needed by older people. Our Community Options Program provides considerable choice of providers so that it is possible to employ neighbors, friends, or relatives to keep someone at home, and older people can choose between congregate day care or in-home services. Case managers are encouraged to respond to consumer needs and preferences while maintaining strict eligibility control.

State agencies on aging have increasingly diversified their roles, including developing standards, training curricula, consumer education, legal assistance to community care clients, and quality assurance. In Wisconsin the long-term care ombudsman is responsible for handling complaints in the home and community care system. In many States the State unit administers the home and community care program and the Medicaid waivers.

Senator Feingold, who was a leading advocate for Community Options in our State Senate—he was the leading advocate for Community Options in our State Senate—knows how urgently older people and persons with disabilities have expressed their desire to be valued and respected by being allowed to receive long-term care in the places they choose. Senator Feingold also knows that he was able to work in bipartisan fashion with Governor Tommy Thompson to achieve the steady expansion of Community Options because of its positive fiscal impact. Consistently, Community Options clients cost less than comparable residents of nursing homes.

In conclusion, let me say that in Wisconsin the key elements of successful reform of long-term care require adherence to the following principles: reducing the policy and financial bias favoring institutional care to pursue the expansion of options and choices for home care; targeting resources carefully and objectively to those most in need; and providing maximum flexibility and authority at the level of the consumer's care manager to increase the likelihood that the person will receive what she wants and needs at the lowest possible cost. That means flexibility in the choice of provider, the use of informal supports, the range of care settings, and the individual's own determination of allowable risk.

These are principles which have been formulated and advanced by State units on aging across the country, which reflect the advocacy orientation of the aging network and the fiscal prudence which characterizes the network as well. State units on aging have demonstrated that respect for the individual is not inconsistent with sound fiscal management and successful program outcomes.

Thank you very much for the opportunity to be here today.

[The prepared statement of Ms. McDowell follows:]

Tommy G. Thompson
Governor

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STATEMENT OF

DONNA MCDOWELL, DIRECTOR

BUREAU ON AGING

WISCONSIN DEPARTMENT OF HEALTH AND SOCIAL SERVICES

Mr. Chairman and distinguished members of the Senate Special Committee on Aging, I am Donna McDowell, Director of the Wisconsin Bureau on Aging in the Department of Health and Social Services, which is the State Unit on Aging in Wisconsin. I am also currently serving as President of the National Association of State Units on Aging (NASUA), which represents the state-level aging network across the country. I bring greetings from home to our two respected Senators, Senator Herb Kohl and Senator Russell Feingold.

The aging network has long recognized that reform of long term care is a central issue for older people in all of our states and communities. In the past 15 years, states initiated efforts to deliver long term care in home and community settings; many states have fully implemented statewide systems of community based care, and most have at least the infrastructure of a delivery system in place. In 1987, based upon these state experiences, NASUA published a policy statement framed by all the state aging units, calling for a radical restructuring of the long term care with the central purpose of ending the institutional bias in long term care.

The role of the state aging network from the beginning has been leadership in driving the policy debate toward a more consumer-centered view of long term care. We have been the principle architects of long term care reform at the state level, working to assure that the views and preferences of older persons, and younger persons with disabilities, were systematically incorporated into the design of new long term care programs. We are pleased and hopeful that the new Assistant Secretary for Aging, Dr. Fernando Torres-Gil, will exert the same influence on long term care reform here in Washington.

The Wisconsin Community Options Program is one very good example of the success of state efforts for reform. In 1982, in a bi-partisan effort spearheaded by a Republican Governor, Lee Dreyfus, and a predominantly Democratic state legislature, the state embarked on a restructuring of long term care which had three critical characteristics:

1. A moratorium was placed on the construction or expansion of nursing homes to contain Medicaid costs.
2. New long term care resources were directed exclusively at a carefully designed, consumer-centered model of home care called Community Options, administered by 72 counties.
3. A target population of beneficiaries was carefully defined to limit benefits to those persons of any age who would otherwise qualify for institutional care, whether elderly, physically disabled, chronically mentally ill or developmentally disabled adults or children.

Like most other state programs, the Wisconsin Community Options Program relies on case management. A skilled social worker, teamed with a nurse, visits the older person to assess what basic daily activities the person can manage, and what functions he or she needs help with. The case manager also assesses the environment in which the person has chosen to live to see what home modifications or equipment can increase the persons safety and self-sufficiency. The assessment also identifies family and friends who are currently helping out or who could be enlisted to give help. And most importantly, the assessment determines what the older person's own personal aspirations and preferences are to establish the goals of the program for the individual. The case manager's job is to mobilize, and authorize payment for, the formal and informal supports that will realize the consumer's goals. A consumer-centered system of care takes into account the unique needs and resources of each person. And in the process often saves money.

Those of us who have designed and delivered services to older people have learned that the reform of long term care means moving away from a medical orientation of professional diagnosis and medical procedures to focus on maintaining the individual's ability to function as much as possible in a familiar setting in ways that keep them confident and comfortable. State units on aging, like Wisconsin's, have been advocates, planners and administrators who are reshaping the idea and the operation of long term care programs to reflect the goals and aspirations of a very diverse and growing number of individuals. We are trying to restructure long term care for the majority of older persons who choose to stay at home, or move to new homes which offer services, without loss of privacy or autonomy. We have designed community care programs in which case managers are responsible for the well-being of older persons and accountable only to the consumer and the government payor, not to a provider.

To accomplish this mission, Wisconsin has made very explicit policy decisions that are necessary to reinforce this consumer responsiveness. For example, Wisconsin will use public funds to support any service needed by older people. Our Community Options Program provides considerable choice of providers, so that it is possible to employ neighbors, friends or relatives to keep someone at home. Older people can choose between congregate day care or in-home service. Our state legislation and rules require consumer involvement in county program planning, in the development of individual care plans, in quality assurance, etc. Case managers are encouraged to respond to consumer needs and preferences, while maintaining strict eligibility control. County case management agencies are accountable for meeting program goals within fixed budget constraints.

State agencies on aging have increasingly diversified their roles, including developing standards, training curricula, consumer education, legal assistance to community care clients, and quality assurance. In Wisconsin, the OAA Long Term Care Ombudsman is responsible for handling complaints in the home and community care system. Seventy-five percent of state-funded community care programs are administered by state units on aging, and about half of the Medicaid home and community-based waiver programs are directed by state units on aging. The Wisconsin Bureau on Aging has also successfully applied for numerous discretionary grants from the Administration on Aging. Title IV grants, as well as state funds, have provided important support for the developing infrastructure of Wisconsin's Community Options Program; for new approaches to defining quality; for case management standards; to demonstrate a successful linkage between hospitals and home care, etc.

Senator Feingold, who was a leading advocate for Community Options in our state Senate, knows how urgently older people and persons with disabilities expressed their desire to be valued and respected by being allowed to receive long term care in the places they chose. Senator Feingold also knows that he was able to work in bi-partisan fashion with Governor Tommy Thompson to achieve the steady expansion of Community Options because of its positive fiscal impact. Consistently, Community Options clients cost less than comparable residents of nursing homes.

In Wisconsin, the key elements of successful reform of long term care require adherence to the following principles:

- Reduce the policy and financial bias favoring institutional care and pursue the expansion of options and choices for home and community care.
- Target resources carefully and objectively to those most in need of this comprehensive care.
- Provide maximum flexibility and authority at the level of the consumer's care manager to increase the likelihood that the person will receive the care they want and need at the lowest possible cost. That means flexibility in the choice of provider, the use of informal supports, the range of care settings and the individual's own determination of allowable risk.

These are principles which have been formulated and advanced by state units on aging which reflect the advocacy orientation and fiscal prudence which characterize the aging network. The Wisconsin aging network has long operated on the principles of valuing the dignity and worth of older persons and the pursuit of meaningful roles and activities without regard to age or disability. We believe that it is the principles embodied in the Older Americans Act which need to also shape the restructuring of long term care. The Wisconsin statement of RESPECT which forms the basis for our definitions of quality is provided to you for the record. State Units on Aging have demonstrated that respect for the individual is not inconsistent with sound fiscal management and successful program outcomes.

Thank you for the opportunity to appear here today.

Wisconsin Long Term Support for Elderly and Disabled People
Is Based on
RESPECT

RELATIONSHIPS.

EMPOWERMENT TO MAKE CHOICES.

SERVICES TO MEET INDIVIDUAL NEEDS.

PHYSICAL AND MENTAL HEALTH.

ENHANCEMENT OF PARTICIPANT REPUTATION.

COMMUNITY AND FAMILY PARTICIPATION.

TOOLS FOR INDEPENDENCE.

Wisconsin Long Term Support for Elderly and Disabled People
Is Based on
RESPECT

RELATIONSHIPS. Relationships between participants, care managers,and providers are based on caring, respect, continuity over time and a sense of partnership.

People who work in long term support programs care about the people who apply for and receive services. A respectful human relationship with program participants is part of the job responsibilities of all the staff -- the receptionist who answers the phone, the case manager who helps determine eligibility and develop service plans, the inhome worker who provides personal care, and everyone else who works with the participant. Planning and managing services can be approached as a partnership between the participant and the case manager, each contributing to the solving of problems related to the participant's disability.

Continuity of relationships is also important. Long term relationships should be sought between care managers and program participants, and between service providers and participants.

EMPOWERMENT TO MAKE CHOICES. Individual choice is the foundation of ethical long term support services.

People have preferences about how they live everyday life: where they live, whether alone or with someone, and how they spend their time. Long term support services which are truly individualized help people express their preferences and personal values and, to the extent possible, meet those preferences. Programs of quality empower and enable participants to determine what services they receive, how the services are provided, and who provides them. Case managers can be consultants for participant choice, assuring that participants have all the information and time they need to make meaningful decisions about long term service.

Wisconsin's philosophy of respect for choice recognizes the dignity of individual risk-taking to maintain a measure of independence, and the right to experience one's preferred level of safety from physical harm, environmental hazards and exploitation.

SERVICES TO MEET INDIVIDUAL NEEDS. Individuals want prompt and easy access to services that are tailored to their individual circumstances.

A frail elderly or disabled person ought to get needed services easily...without red tape, confusing or difficult experiences or delay. Sufficient services need to be funded to meet each individual's needs, rather than serving many persons inadequately.

Planning services around individuals requires variety, flexibility, and creativity. Many different types of services are required in a community to meet differing needs and preferences. Good services promote people's optimum health, security and functioning. Stability of services is also important. People should be able to feel secure that their services are guaranteed by the system, and will be provided without interruption or unplanned changes.

PHYSICAL AND MENTAL HEALTH. Services are intended to help people achieve their best level of health and functioning.

People come to need long term support services because they have difficult health problems. These problems must be addressed directly to help people optimize their quality of life. Excellent health care and rehabilitative services are a fundamental part of the long term support program. These include services to maintain wellness and prevent illness and injury, as well as services to treat illness, injury, pain and disability.

Care plans that work well for participants integrate and coordinate all the health care and social supports needed by the individual. Health and social service professionals need to function as teams to meet needs comprehensively.

ENHANCEMENT OF PARTICIPANT REPUTATION. In every way possible, long term support services maintain and enhance each participant's sense of self-worth and the community's recognition of his or her value.

Participants are perceived and treated with respect, as persons of value. Service design and delivery reflect each individual's past, present and future strengths and characteristics.

Case managers and providers do not treat adults as children, nor any participant as an objectified "case." Services are managed and provided in a way that respects the personal privacy of participants, assuring that care is provided as nonintrusively as possible and that information about the participant and his or her services is kept confidential.

COMMUNITY AND FAMILY PARTICIPATION. Participants are supported to maintain and develop friendships and to participate in their families and communities.

Services are designed to help people maintain the relationships and roles that are already part of their lives. Services are also offered to help people develop new relationships and activities, if that is their desire. Services enable people to actively contribute to their communities, both for their own satisfaction and the good of their communities. Respect is also given to an individual's expressed need for privacy and non-participation; social interaction is not forced on the participant.

TOOLS FOR INDEPENDENCE. People are supported to achieve maximum self-sufficiency and independence.

People generally want opportunities to take care of themselves as much as they are able. Because of disabilities or health problems, people may need support to carry out many everyday tasks. Tools that would enable people to do those tasks by themselves should be preferred to other types of assistance, when that is possible and preferred by the individual.

The CHAIRMAN. Ms. McDowell, we appreciate very much your coming from a long distance and giving us the benefit of your testimony. I'm going to ask a couple of questions in a moment, after Mr. Wilson completes his testimony.

Mr. Wilson, we're proud to have you here today, and, once again, we appreciate your coming a long way.

STATEMENT OF JAMES C. WILSON, ADMINISTRATOR, OREGON SENIOR AND DISABLED SERVICES DIVISION, PORTLAND, OR

Mr. WALKER. Thank you, Mr. Chairman. Mr. Chairman, for the record, my name is James Wilson. I'm Administrator of Oregon's Senior and Disabled Services Division, and I'm honored to speak to you today about the role Oregon's aging network plays in the delivery of home and community-based services in our State. That network really consists of three components. The first is the aging agency, of which I'm in charge; the second are elderly advocates; and the third are the area agencies on aging. Let me talk just a second about each component.

First, our State agency on aging. It is unique among State agencies in the United States in that it is not only the State agency on aging, it is the agency which administers the long-term care component of the Medicaid Program in our State. Actually, about 70 percent of our agency's funding comes through the Medicaid Program. Only about 6 percent comes through the Older Americans Act. The delivery of both of these programs is accomplished at the local level by area agencies on aging, so you actually have area agencies on aging in this State administering a Medicaid Program.

Our agency was established in 1981 by the Oregon Legislature as a result of considerable lobbying by elderly advocates. Prior to that time, our system was very much like many of those you still see in the United States today. We had a small State agency on aging which administered a very small State-only funded community-based care system. We had a very large and expensive nursing home program. The senior citizens in Oregon were not happy with that set of circumstances, and it was through their efforts that our agency was established in 1981, on the last day of the longest legislative session in Oregon's history. So we just barely squeaked through.

When our agency was established, it mandated in statute that I, as the aging administrator, emphasize home and community-based care. Now, fortuitously, during that same year, Congress passed the Medicaid home and community-based care waiver authority, and that helped us tremendously. I might mention that in the 1979–81 biennium, we were serving about 9,000 people in nursing homes in Oregon. By the end of the first year we were an agency, we had managed to cut that to about 8,000 people and diverted those people into community-based settings where they receive good care. As of last week, we were serving 7,389 persons in nursing homes. Granted, we are serving a lot of people in community-based care programs today, about 12,000 in Oregon, but we're able to do so at an average monthly cost of about $475 net to our agency. Our net cost for nursing home care is about $1,800 a month.

We've done this in spite of the fact that the growth of the age 75-and-above population in our State has averaged over 3 percent

through the last 10 years. Quality of care in our community-based care system is excellent. I can't tell you the number of times we've had learned outside groups come and investigate that type of care, and they, without exception, have walked away saying, "This is great. This is better than putting people in institutions."

Let me talk a little bit about the other two components of the system. First, the elderly and disabled advocates. They continue to play a very powerful role in the way services are delivered in our State. There is not a day that goes by that I don't have a visit from one member or another of the Governor's Commission on Aging, especially during a legislative session, and they're working with us constantly. They also perform a very important function: they tell me when we're goofing up, and they get me back on the right track.

The area agencies on aging perform several very important functions. They do administer our programs locally. Donna McDowell talked about probably the most important function area agencies perform, and that is case management, and I won't try to describe that in any more detail.

The system works. We looked at how much each of the various States were spending on their Medicaid long-term care programs during 1990. We then divided those dollars by the number of persons 65 and over in each of the States. Oregon is spending or did spend in 1990 about $448 per year in Medicaid long-term care funds for every person age 65 in the State. That's about one-fourth of what it's costing in the most expensive State.

For those who would argue that there is a woodwork effect and that we're serving too many people, I would point out that our expenditures per person age 65 in Oregon are 40th from the top of the list of all the States. The system works. We're able to provide good care at a very reasonable cost.

The Older Americans Act, to sum up, provides us with our philosophical guiding light, the Medicaid Waiver Program is the engine that makes the train move, the AAAs deliver the goods, and the elderly and disabled advocates keep us on the track.

Thank you.

[The prepared statement of Mr. Wilson follows:]

James C. Wilson
Administrator
Oregon Senior and Disabled Services Division
(503) 378-4728

Mr. Chairman, members of the committee, my name is James Wilson. I am the Administrator of Oregon's Senior and Disabled Services Division. I am honored to have been asked to speak to you today about the role Oregon's aging network plays in the delivery of home and community based services in our state.

Before doing that I would like to tell you a little bit about our Agency, because it is unique among state aging agencies in the United States.

Oregon's Senior and Disabled Services Division was created by our legislature in 1981 as a result of a ground swell of feeling among Oregon's elderly and disabled population that a state ought to offer elderly and disabled persons a choice of more than just nursing home care if they need long term care. Our agency is unique in that it administers not only all Older Americans Act programs, but also all of the State's medicaid funded long term care services and the cash assistance and food stamp programs for the elderly and disabled. It does this primarily through local government sponsored Area Agencies on Aging.

Prior to 1981 Oregon administered its long term care services in much the same manner that they are still administered in most states. The state aging agency was part of a human services umbrella agency. It administered the Older Americans Act programs through eighteen Area Agencies on Aging which were either private non profit organizations or were sponsored by some local government entity such as a county or a council of governments. It also

administered a very small state funded in-home care program called "Oregon Project Independence." The medicaid program was administered by the state's "welfare" agency. Although it too was part of the same human services umbrella agency, all of its employees worked for the state and there was very little coordination between it and the State Office on Aging, and even less at the local level. As in many states the long term care part of the state's medicaid budget was growing by leaps and bounds, as were medicaid financed nursing home caseloads.

It was this set of circumstances which upset many of the more astute elderly and disabled advocates in the State. They found a willing partner in a State legislature which was growing weary of seeing an ever increasing portion of the state's budget going to pay the costs of a few persons receiving nursing home care. Fortuitously, Congress, during that same year, made it possible, through the medicaid home and community based care waiver legislation, for our state to start right away on an ambitious program to divert significant numbers of people from nursing homes to community based care.

What has been the result of this "experiment?"

During our first two years of operation (the 1981/83 biennium) our agency paid for the care of an average of 13,147 persons per day. Of those, 8,061 were in nursing homes and 5,086 were in our medicaid funded community based care system. Today we are paying for the care of 7,389 persons in nursing homes (in spite of the fact that the population of those most at risk of needing nursing home care, those aged 75 and above, has been growing at a rate of over three per cent per year throughout the 1980s) and 12,588 persons in home or community based settings. Our current average monthly net cost per person in a nursing facility is

about $1,800 per month. In community based care it averages $475 per month. Had we continued to serve persons in nursing homes at the same rate, adjusted for population growth and inflation, as we did prior to our agency having been created, we would have spent $108,087,379 more during the last biennium than we actually did. In fact, we estimate that this system saved Oregonians $227,399,379 in the ten years between 1981 and 1991.

In spite of the fact that we are probably financing the care of more persons than we would have had we continued our "nursing home dependent" system, our costs per consumer are among the lowest in the United States. When all the States' annual medicaid long term care expenditures for 1990 are divided by their aged 65 population, and are then arrayed from highest to lowest, Oregon ranks 40th from the top.

Several studies have been done of the quality of care in our community based care system. In every instance the quality of care has been rated as excellent. More important than the learned studies, perhaps, is what we hear daily from Oregonians who use the services provided to them or their relatives. They like them, because they are allowed a choice to remain in their own homes or a home like setting.

Now to the issue I was asked to address. What role does the aging network play in the delivery of home and community based services in Oregon?

The key players in that "network" are persons I will broadly characterize as advocates for the elderly and disabled, and the eighteen local Area Agencies on Aging. I believe I have probably answered most of the questions you might have regarding the role played by the advocates. Since it was the advocates who wanted this system, they feel considerable ownership in it. They remain very active in setting agency's over-all direction. That direction continues to be very much in

favor of community based care. As a practical matter, this allowed those of us who administer the agency to counterbalance the considerable political influence of provider interest groups. We enjoy a situation where the two large associations representing nursing homes in our state have agreed that the community based care system is an important component of a continuum of long term care services and both have members which are also community based care providers.

Elderly and disabled advocates are able to exert influence on policy at both the local and the state level. Each Area Agency on Aging has an advisory council, and, in those geographic areas where the AAA has decided to manage the provision of services to younger disabled persons, they are also advised by a separate council representing younger disabled persons. At the State level, our agency is advised by a Governor's Commission on Senior Services and a Disability Services Commission.

Our programs are, by and large, locally administered by Area Agencies on Aging. (Some smaller non-profit AAAs in the Eastern part of the State have chosen not to administer the medicaid part of the program. In those areas, the state continues to administer them). The State sets over-all policy, but relies heavily on input from the Association of Area Agencies on Aging in doing so. I and my executive staff meet frequently with the executive board of the Association, and we are in constant communication with one

another on strategic issues. This, in my opinion, has strengthened the system. Local managers are granted the maximum amount of flexibility possible, while still remaining in compliance with the federal laws and regulations which apply to the programs delivered by us. The system has encouraged creativity and innovation. Also, even though our State law does not require it, many local entities contribute to the costs of programs where they feel the program should be enhanced. The over-all costs of administering the programs is slightly less than it would have been, had the State continued administering them.

Local Area Agency on Aging staff perform many important functions, including licensing community based care facilities, screening all persons for financial eligibility, and coordinating with other locally sponsored programs. The Area Agencies have been able to maximize the impact of both Title XIX and Older Americans Act funding.

Perhaps the most important function local government provides is casemanagement. This is a service which, I believe is best performed at the local level, because local people know how to obtain the best services possible for the money available. It is much more acceptable to the public, because of the general belief that the level of government which works best is that which is closest to you.

Its hard to argue with results! This system works! It uses the Older Americans Act as its philosophical guiding light and the medicaid program as its primary funding mechanism while insuring the best deal possible for the public and consumers.

PHILOSOPHY AND MISSION

THE SENIOR AND DISABLED SERVICES DIVISION'S PHILOSOPHY

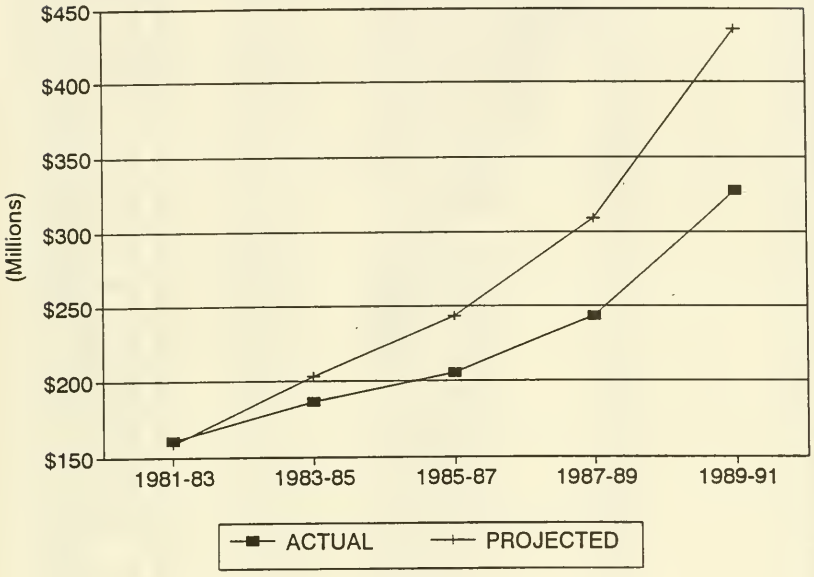
The legislation which created the Senior Services Division (Senate Bill 955 of the 1981 Session; ORS 410), states the Agency's mission and has provided it with a clear philosophical foundation. It says:

> The State of Oregon finds that the needs of the elderly population can best be served and planned for at the community level; that a longer life expectancy and a growing elderly population demands services be provided in a coordinated manner and a single local agency system for such services instituted; that local resources and volunteer help will augment state funds and needed manpower; that local flexibility in providing services should be encouraged; that the elderly citizens of Oregon will receive the necessary care and services at the least cost and in the least confining situation. The State of Oregon further finds that within budgetary constraints, it is appropriate that savings in nursing home services allocations within a planning and services area be reallocated to alternative care services under Title XIX, Title XX, and Oregon Project Independence in that area.

The Senior and Disabled Services Division is committed to those concepts. It is also committed to providing services to elderly and disabled individuals through programs and in settings which maximize their ability to function as independently as possible given their physical limitations and which encourage the principles of personal dignity, individuality, privacy, the right to make choices, and the right to a decent quality of life.

WHAT HAS BEEN ACCOMPLISHED

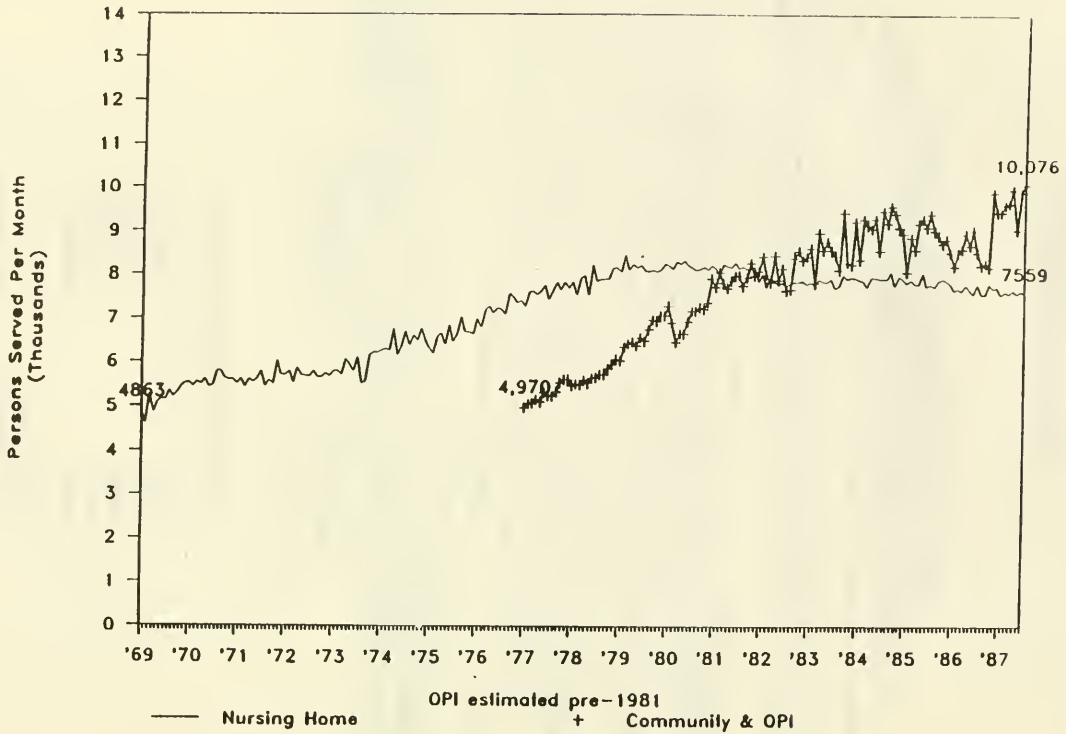
TOTAL LONG-TERM CARE COSTS
ACTUAL VS PROJECTED BASED ON '79 LEVELS



CUMULATIVE SAVINGS PER BIENNIUM

1981-83	($2,006,777)
1983-85	$16,833,044
1985-87	$38,219,952
1987-89	$66,266,357
1989-91	$108,087,379
TOTAL SAVINGS 1981 TO 1991	$227,399,956

Nursing Home & Community Base Caseloads



Federal Fiscal Year 1990 Long-term Care Expenditures Per Person 65+

	State	*1990 65+ Population	1990 LTC Costs	Costs Per Person 65+	% of 1990 Population Over 65
1	NEW YORK	2,363,722	$4,590,786,710	$1,942	13%
2	ALASKA	22,369	$35,867,849	$1,603	4%
3	MASSACHUSETTS	819,284	$1,237,766,247	$1,511	14%
4	CONNECTICUT	445,907	$655,042,711	$1,469	14%
5	DIST OF COL	77,847	$108,809,929	$1,398	13%
6	MINNESOTA	546,934	$653,697,244	$1,195	13%
7	MAINE	163,373	$185,141,976	$1,133	13%
8	NEW HAMPSHIRE	125,029	$141,287,268	$1,130	11%
9	RHODE ISLAND	150,547	$164,106,421	$1,090	15%
10	WISCONSIN	651,818	$615,937,254	$945	13%
11	NORTH DAKOTA	91,055	$85,412,666	$938	14%
12	VERMONT	66,163	$59,389,933	$898	12%
13	NEW JERSEY	1,032,025	$860,932,582	$834	13%
14	OHIO	1,406,961	$1,062,401,739	$755	13%
15	MARYLAND	517,482	$355,437,670	$687	11%
16	WASHINGTON	575,288	$389,522,988	$677	12%
17	INDIANA	696,196	$470,799,760	$676	12%
18	COLORADO	329,443	$215,919,154	$655	10%
19	SOUTH DAKOTA	102,331	$66,867,383	$653	14%
20	MONTANA	106,497	$69,221,440	$650	13%
21	HAWAII	125,005	$80,717,229	$646	11%
22	DELAWARE	80,735	$51,785,760	$641	12%
23	GEORGIA	654,270	$412,584,428	$631	10%
24	KENTUCKY	466,845	$290,865,431	$623	13%
25	LOUISIANA	468,991	$288,240,519	$615	11%
26	PENNSYLVANIA	1,829,106	$1,097,144,078	$600	16%
27	WEST VIRGINIA	268,897	$158,669,890	$590	15%
28	ARKANSAS	350,058	$206,415,809	$590	15%
29	NEBRASKA	223,068	$127,794,593	$573	14%
30	NORTH CAROLIN	804,341	$430,643,599	$535	12%
31	MICHIGAN	1,108,461	$584,015,970	$527	12%
32	OKLAHOMA	424,213	$213,835,699	$504	13%
33	NEW MEXICO	163,062	$80,847,165	$496	11%
34	WYOMING	47,195	$23,281,015	$493	10%
35	TENNESSEE	618,818	$296,952,498	$480	13%
36	MISSISSIPPI	321,284	$153,030,146	$476	12%
37	TEXAS	1,716,576	$803,796,263	$468	10%
38	VIRGINIA	664,470	$310,216,377	$467	11%
39	MISSOURI	717,681	$332,518,442	$463	14%
40	OREGON	391,324	$175,492,044	$448	14%
41	CALIFORNIA	3,135,552	$1,388,749,533	$443	11%
42	KANSAS	342,571	$148,083,823	$432	14%
43	UTAH	149,958	$64,701,836	$431	9%
44	ILLINOIS	1,436,545	$616,794,611	$429	12%
45	IDAHO	121,265	$51,181,800	$422	12%
46	SOUTH CAROLIN	396,935	$165,890,511	$418	11%
47	ALABAMA	522,989	$211,861,190	$405	13%
48	IOWA	426,106	$160,062,964	$376	16%
49	NEVADA	127,631	$43,404,759	$340	11%
50	FLORIDA	2,369,431	$597,305,223	$252	18%
51	ARIZONA	478,774	$51,364,387	$107	13%
	TOTALS	31,242,428	$21,642,596,516	$693	

*U.S. Bureau of Census CB 91-217 (6/11/91)

The CHAIRMAN. Mr. Wilson, let me ask you a question. How did you convince the—I hate to call it the nursing home industry; why don't we call it the nursing home administrators—in your State of Oregon that this new system of community-based care over nursing home care would work? Was that a big problem with you?

Mr. WILSON. That was not a simple problem, and the education process still goes on. But the nursing home administrators in our State, at least, understand that there are alternatives, and in order to compete, they have to offer good quality care, or others will do it at a lower cost.

The CHAIRMAN. Now, you were comparing a moment ago the costs of—was that home health care or community-based?

Mr. WILSON. That's our entire community-based system average cost.

The CHAIRMAN. Community-based system versus institutionalization of the individual.

Mr. WILSON. That's correct, sir.

The CHAIRMAN. Now, are you going to be a part of helping Dr. Torres-Gil with this spaghetti chart and trying to not only understand this, but simplifying the system? I don't see how anything gets done with a system like this. Are you going to be a part of that?

Ms. McDowell, are you going to be a part of that reform effort? I hope you will.

Ms. MCDOWELL. We do hope to be.

The CHAIRMAN. You've done some unique things out there in your States, and I think that the Federal system has a lot to learn from you, because you're out there on a daily basis delivering these services, and we admire and respect that very much. Do you have any statistics you might like to share as to how you might have prevented an individual from being institutionalized in a nursing home or in a hospital? Do you have any statistics as to how you lengthened the stay at home?

Mr. WILSON. Well, Mr. Chairman, the average length of stay in community-based care does tend to be longer than it is in nursing home care. People live longer in community-based care. They're happier. It's about three times as long, 3 years compared to a little over 1. We still estimate, even after all of the years that we've spent, that about 30 percent of the people who are in nursing homes could be cared for just as well in a community-based setting. There are always a certain number of persons who will need nursing home care, and we're not trying to displace nursing home care as a program, but a lot of the people can be cared for in their own homes.

The CHAIRMAN. Senator Feingold.

Senator FEINGOLD. Thank you, Mr. Chairman. I think this point about the State programs, I want to bring out something a little more specific with regard to the Wisconsin program and what level of benefits are going to be provided. One of the real problems is that we've created a new Federal program and we provide certain benefits. We may provide them to everybody, and they may not be the benefits that certain people need.

So one feature that I'd ask Donna to bring out is not having a list of specific benefits for which people would be eligible; instead,

with a few exceptions, the possibility of allowing beneficiaries to receive any service that will help them maintain their independence in their own home or other community setting. If you could spend a couple more seconds, Donna, on the experience of this sort of nonlimiting approach to services and comment on how that fits in with the entire framework of long-term care.

Ms. McDOWELL. Thank you, Senator, for the question and the opportunity to answer it. We do find from our experience that both the level of consumer satisfaction and the cost savings that we've achieved have been because we've been able to offer a very flexible benefit, and we will pay for virtually anything that will enable someone to stay at home, including the kind of home modification that Senator Cohen referred to, the capacity to pay neighbors to provide services at times at which it's difficult to get agencies to provide services, and so on. The consumer-centered notion of care means that we tie the funding to what the individual needs as opposed to tying the funding to a set of providers listed on a menu, and we think that has a lot to do with the kind of cost savings we've achieved, which, although I describe them differently than Jim, are certainly comparable to Oregon's.

Mr. WILSON. Senator Feingold, if I might add, I heartily endorse the notion of not giving us a menu and asking us to select from the menu. In Oregon, for instance, the primary alternative to nursing home care is adult foster care. Now, most other States don't use adult foster care to a large extent, but we do. We're able to divert people from nursing homes, people who have actually been in nursing homes, to adult foster care and to what we call assisted living more successfully than any other type of care. Home care is great as a preventive mode, but once a person is in a nursing home and if they need somewhere else to go, they have often lost their home and they need a homelike alternative.

So we would urge you to give the States flexibility to build programs that work well in those States.

Senator FEINGOLD. I think sometimes when people, like the folks that are working on this in the Administration, are looking at how much it's going to cost to have a new system, they look at a service, whether it be physical therapy or whatever, and assume that a great number of people will need it or that everyone might use it, and that's not reality. It's better to use a case manager approach, somebody who can identify what's really needed, and perhaps the cost won't seem quite as severe.

I'm wondering if Donna or Jim, either of you, would comment a little bit more about this idea of relying on friends and family members for some services, as we've done in Wisconsin. To me, it's always been a great aspect of the program. For some, it raises questions of quality control and supervision. I'm wondering if you can give a sense of how that's been dealt with.

Ms. McDOWELL. As you well know, the use of family and friends and neighbors in the Community Options Program has been particularly important in areas where there are shortages of formal providers. When there isn't enough capacity to provide service around-the-clock, at odd hours, in out-of-the-way rural locations or in urban neighborhoods that are not well served by agencies—

we've overcome those obstacles because we've allowed the payment of neighbors and relatives.

This flexibility also enables people to live a more normal life. If agencies will only provide services up until 6 at night and someone wants to stay up until 11 and then go to bed, you need to be able to pay the neighbor to come in and help her into bed, or you're going to make everybody go to bed at 6. So, again, the consumer focus of the program really demands that kind of flexibility.

In the sorts of quality reviews that we do, and I'm sure Oregon does, where we do random samples, go in and have face-to-face interviews with clients, and also monitor the care plans, we have no evidence of quality problems in those circumstances. In fact, the level of satisfaction seems to be most high where people are cared for by someone they know and trust rather than by strangers.

Senator FEINGOLD. I think the point is true in any State having to do with friends and families, but in particular States like the Chairman's, my State, rural areas, this becomes even more important.

I have no more questions. I just want to say that when you take political science in school, the States of Oregon and Wisconsin are often linked for their progressive politics, and I think this is a wonderful example of those two States continuing that tradition.

Thank you, Mr. Chairman.

The CHAIRMAN. We do want to compliment each of your States. We've learned a great deal. That's one of the purposes of a hearing like this, to share information, and that is one of the reasons this Committee exists today to do this, and we want to thank you for it.

We're going to leave the hearing record open a few days, as there may be some follow-up questions. I'm wondering if there's any final comments either of you would like to make.

Mr. Wilson, we thank you, and, Ms. McDowell, we thank you very much, and we appreciate your attendance here and sharing your testimony with us.

We will call our third and final panel. Elaine Eubank is the Director of the Central Arkansas Area Agency on Aging, from North Little Rock—we appreciate your being here, Elaine; Donna Sargent, Director of Health Services, Community Health and Counseling Services, from Bangor, Maine; and Frances Hicks, caregiver, of Alexandria, Virginia.

We appreciate the three of you being here this morning, and we'd like for you once again to be reminded as gently as I can say it as to our problem with time. We do apologize for that and hope that we can get through our testimony and perhaps one or two questions.

We have the arrival of Senator Grassley of Iowa, who's a very faithful Member of the Special Committee on Aging.

Senator Grassley, this is our final panel this morning. We've been talking about the area agency on aging networks and our whole aging network as to how it is going to assist us in long-term care. We do have two back-to-back votes at 11:30, but before I proceed to go forward with the testimony, would there be any comments that Senator Grassley might have?

STATEMENT OF SENATOR CHARLES GRASSLEY

Senator GRASSLEY. I will not make an opening statement. I'll put it in the record and just simply say to you, Mr. Chairman, that over a long period of time, even before long-term health care became a national issue, I've had members of our organizations in Iowa, particularly those with the AAAs, who have expressed an interest over a long period of time in helping out and feel that, to some extent, under the system we have now they're in a place of advocacy and trying to help.

The CHAIRMAN. And they're also in a position of teaching us a lot of the things that we should know and sharing their thoughts with us. We hope many of these thoughts and ideas will be implemented and be made a part of our overall long-term health care strategy.

Senator GRASSLEY. I'll put my statement in the record.

The CHAIRMAN. Without objection, your prepared statement will appear in the record, Senator Grassley.

[The prepared statement of Senator Grassley follows:]

PREPARED STATEMENT OF SENATOR CHARLES E. GRASSLEY

Mr. Chairman, this is a very useful hearing.

The Older Americans Act network now in many States is very important to the provisions of long-term care services for older Americans.

Its information and referral services, and case management services, in many parts of the country, make the difference between a system which is impenetrable and user unfriendly, and one in which older persons and their families are better able to find and use available services.

The home health care and means programs, and the other programs it sponsors may be the only such services in a community.

Now we may be about to undertake health care reform. And this reform could include improvements in our long-term care system.

So I want to take this opportunity to note, Mr. Chairman, that I agree with the assumption underlying your hearing. That is, that the Older Americans Act network should have a major role in any reformed long-term care system.

The Older Americans Act network is potentially capable of providing the framework for coordinating long-term care services at the community level. Area agencies on aging can by-and-large act in a disinterested and objective way in coordinating services. They are capable of acting primarily as advocates for older Americans in need of long-term care services.

There are of course, great differences in the capacity of triple-A's across the country. This has often been noted. Some are strong and well-staffed and capable of playing a major role. Others are not. This variation in capacity is a problem that would have to be dealt with in any reformed system in which the network has a major role.

In any case, I'm looking forward to the day when the Older Americans Act network can reach its full potential in the long-term care system.

With that I'm almost finished, Mr. Chairman. I would just like to conclude by welcoming our new Assistant Secretary on Aging to the Special Committee. I am one of those who advocated for many years the elevation of the status of the then Commissioner on Aging in the Department. So I am very pleased to have Mr. Torres-Gil before us as Assistant Secretary.

The CHAIRMAN. Elaine, we look forward to your statement. Thank you.

STATEMENT OF ELAINE EUBANK, EXECUTIVE DIRECTOR, CENTRAL ARKANSAS AREA AGENCY ON AGING, NORTH LITTLE ROCK, ARKANSAS

Ms. EUBANK. Thank you for the opportunity to talk with you this morning about the aging network and long-term care. I represent

the area agency on aging in North Little Rock, Arkansas. We serve over 15,000 clients a year in the six-county region in the central portion of the State. We operate with a $6.5 million budget, 400 employees, and six contractual service providers. We're one component of a statewide and a nationwide system of home and community-based care called the aging network.

As an agency, we offer a wide range of services, and they're outlined in this handout that you all got that's on the back of your testimony. On a continuum, we serve older people functioning at very different levels with different service needs. For example, we serve independent older people in employment and senior center programs, and very frail and dependent elders in our in-home programs.

We offer options. Older people want to remain at home as long as possible. A client can choose to receive services at home rather than in a nursing home, and since people have choices, social model programs, like meals or chores, are available as cost-effective alternatives to higher levels of care.

As you can see from the chart, we're involved in several different types of services. We offer access services, like information and referral and transportation, that help older people find needed services. We also offer care coordination to help older people determine what services they need, what benefits they're eligible for, and to help them coordinate the services they receive because of the maze on the chart that you've all seen. As we've discussed, this is not a user-friendly system.

The people we serve are as diverse as our services. We serve mostly low-income and minority clients with our Federal and State grants. In our Medicaid and Medicare funded in-home services, we simply serve the clients who are eligible for the service. We believe our mission is to serve all older people, so we work very hard to find private contracts, private insurance, and private pay for the many, many clients who call us that don't fit into one of the slots.

The aging network itself is diverse. It includes 670 area agencies on aging, 20,000 services providers. The combined network budget is over $2 billion per year. Some aging network agencies are private nonprofits, some units of government. Some offer a standard menu of services, like information and meals and transportation, and others like our agency offer a more full range of services. Even though the characteristics of each agency are different, our mission is the same, and through our network we provide services to every State in the country.

We don't know what our new system of long-term care will look like, but the aging network has experience with the likely components. Area agencies could function in several different roles—as the assessment and coordination component, the service delivery component, or in small States, even in some combination of the two roles.

Duplication of services is a major factor in the high cost of health care, and I hope we won't recreate the wheel in long-term care. It would be more workable and more cost effective to expand the existing structure as needed than to duplicate it. The aging network has a long and successful track record in home and community-

based care. It's the logical framework for a national system of long-term care and should be an integral part of health care reform.

Thank you.

[The prepared statement of Ms. Eubank follows:]

THE AGING NETWORK:

LINKING OLDER AMERICANS TO LONG-TERM CARE SERVICES

Statement of
Elaine Eubank, Executive Director
Central Arkansas Area Agency on Aging
North Little Rock, Arkansas

Background

Thank you for this opportunity to talk with you about the Aging Network and long-term care. I represent the Area Agency on Aging in North Little Rock, Arkansas. We serve over 15,000 clients a year in a six county region in central Arkansas. Our agency operates with a $6.5 million a year budget, 400 employees, and 6 contractual service providers. We are one component of a statewide and nationwide system of home and community based care called the Aging Network.

Services Provided

As an agency, we offer a wide range of services. They are outlined in the chart that is attached.

On a continuum, we serve older people functioning at very different levels with different service needs. For example, we serve independent older clients in senior center and employment programs as well as frail and dependent elders in our in-home programs.

We offer options. Older people want to remain at home as long as possible. A client can chose to receive services at home rather than in a nursing home. And since people have choices, "social model" programs like meals or chore services are available as cost effective alternatives to higher levels of care.

As you can see from the chart, we are involved in several types of services. We offer access services like Outreach, Information and Referral and Transportation that help older people find needed services.

We also offer Care Coordination to help older people determine what services they need and what benefits they are eligible for. The current service delivery system in this county is not user friendly. Our staff locates and coordinates services for clients.

Clients Served

The people we serve are as diverse as our services. We serve mostly low income and minority clients with our federal and state grants. In Medicaid and Medicare funded services, we serve clients who meet the eligibility criteria.

Since we believe our mission is to serve all older people, we solicit private contracts, private insurance and private pay arrangements for clients in the middle and upper income ranges. And we started a fundraising effort to serve clients whose income is too high for government assistance and too low to pay the cost of the service.

Aging Network

The Aging Network itself is diverse. It includes 670 Area Agencies on Aging and 20,000 service providers. The combined network budget is over $2 billion per year.

Some Aging Network agencies are private nonprofits and some units of government. Some offer only a standard menu of services (information assistance, meals and transportation) and others offer a full range of services.

Even though the characteristics of each agency are different, our mission is the same. And through our network, services are provided in every state in the country.

Conclusion

We do not know what our new system of long term care will look like. But the Aging Network has experience with the likely components. We could function in several different roles -- as the assessment and coordination component, the service delivery component, or some combination of the two.

Duplication of services is a major factor in the high cost of health care. I hope we won't recreate the wheel in long term care. It would be more workable and cost effective to expand the existing structure as needed than to duplicate it.

The Aging Network has a long and successful track record in home and community based care. It is the logical framework for a national system of long term care and should be an integral part of our reformed health care system.

Central Arkansas Area Agency on Aging
North Little Rock, Arkansas

Services Provided

Access Services

- Information & Referral
- Care Coordination
- Transportation*

Senior Center Services

- Adult Day Care*
- Senior Center Meals*
- Senior Center Activities*

In Home Services

- Home Delivered Meals*
- Personal Care
- Chore
- Homemaker
- Home Repair*
- Hospice
- Respite
- Senior Companion
- Telephone Reassurance*

Advocacy Services

- Nursing Home Ombudsman
- Legal Assistance*
- Adult Protective Services

Employment

Special Events

*Services Provided on Contract

The CHAIRMAN. By the way, I know you were rushing to beat the clock, but the entirety of your statements will be placed in the record. We wanted all of you to know that, and thank you for coming in within the time period.

Next we'll call on Donna Sargent from the State of Maine.

We appreciate you being here, Ms. Sargent.

STATEMENT OF DONNA SARGENT, DIRECTOR OF HEALTH SERVICES, COMMUNITY HEALTH AND COUNSELING SERVICES, BANGOR, MAINE

Ms. SARGENT. Thank you, Chairman Pryor, Senator Feingold, and Senator Grassley. I thank you for the opportunity to provide testimony here today. As indicated before, my name is Donna Sargent. I'm a nurse and Director of Health Services at Community Health and Counseling Services in Bangor, Maine.

Our not-for-profit agency is unique in that it is a community mental health center as well as a Medicare-certified and State-licensed home health agency. We provide services in a four-county area of northeastern Maine. This region comprises 11,000 square miles and is approximately one and a half times the State of Massachusetts. The area is predominantly rural, with Bangor, a city of 33,000, being the only metropolitan statistical district.

In the most recent fiscal year, my department provided services to 2,600 clients. The services we provide in the home may include nursing, physical therapy, social work, home health aide, homemaker, or, as is often the case, a combination of these services. While we serve all age groups, the vast majority of our clients are elderly. Eighty-six percent are over 60, and of these, 38 percent are over 80. Significant also is the fact that 69 percent live alone, while only 12 percent live with a spouse. I'm sharing these statistics to give you a sense of the population that we have experience in serving.

In Maine we're proud of the network of community health services that exists across the State. In a recent report published by the National Association for Home Care, Maine ranked number 46 among 51 jurisdictions in access to home care and hospice services for its citizens. As the highest ranking was 51, it's evident that Maine has one of the highest ratings in the Nation.

In 1982 the Maine Legislature passed the Home-Based Care Act in an attempt—and I quote—"to increase the availability of in-home and community support services for adults with long-term care needs, who are at greatest risk of being placed inappropriately in an institutional setting." This program was intended to fill the gap in long-term care services to the chronically ill and disabled, caused primarily by restrictions in the traditional funding sources which pay for home care services. These funding restrictions are often arbitrary, having nothing to do with developing the most appropriate plan for the individual. Rather, these restrictions relate to income levels, homebound status, medical necessity, acuteness of health need, hours of care, and length of stay limitations.

The Eastern Area Agency on Aging is responsible for the same geographic area as is covered by my agency. Over 19 percent of the population in this area is over 60, and 25 percent are at or below the poverty line. Therefore, with limited human and fiscal re-

sources, we share the challenge of meeting the needs of this aging population with other service providers in our area. We share with the EAA a common goal of maximizing the home care services for the clients we serve, and we trust in each other's mission and competency.

The EAA provides information and referral services to the older population of our region and has, since 1982, provided case management to the population served under the State-funded Home-Based Care, Medicaid Waiver, and Medicaid Private Duty/Long-Term Care Programs. In their case management capacity, EAA workers determine eligibility for these three programs and function as a conduit between the client in need of services and the agencies providing the service. EAA does not provide in-home services itself, and therein, I believe, lies further explanation for the positive relationship enjoyed in my region of the State between the home health agencies and the agency on aging. This is sorely lacking in other regions of Maine.

In some regions, the area agencies on aging provide in-home services directly, as well as serving as the gatekeeper who controls the referral and the purse strings. This is perceived as a conflict of interest by most providers and is in conflict with the Older Americans Act. At the same time, the area agencies on aging are excluded from State licensing requirements that govern the delivery of home health services. The area agencies usually provide a less expensive care plan because they can utilize personnel who do not have to meet the same training, supervision, and continuing education requirements, as do licensed certified providers.

Conflict between the area agencies and the licensed/certified home health providers arises when the cost of the individual plan of care becomes the determining factor in how the care will be delivered. Under these circumstances, comparisons of the services delivered by the area agencies and the licensed certified agencies become a comparison of apples and oranges.

The State-licensed and federally certified home care industry is intensely regulated. These regulations have been designed to protect the most "at risk" homebound population who are isolated from continuous on-site supervision. These regulations have been developed based on years of experience and input from consumers and providers to protect the public. If in fact these regulatory requirements are critical to the safe and effective delivery of in-home services, then they must apply evenly to everyone providing these services. If they're not necessary, then they must be reexamined and revised so that a true determination can be made as to the quality and the cost of in-home care and a level playing field established for all providers of in-home care.

There is no question that more people of all ages could be cared for at home. Home care in most cases offers the best possible quality of life, is most effective, and many times is more cost effective than other types of health care.

The CHAIRMAN. Ms. Sargent, excuse me. I hate to interrupt you, but we're 5 minutes away from the Senate vote. Could we just put the balance of your statement in the record, or are you just about through?

Ms. SARGENT. I think I am just about finished. I think that the point that I want to make truly is that we need to look at the problems that exist with the current systems in terms of access, in terms of regulations that establish barriers, and we need to look at what isn't working, we need to look at what is working well, and we ought to concentrate on fixing what is broken.

The CHAIRMAN. I'm going to have a final question for the entire panel in a moment that's going to cover some of this, if we have time. We're going to put your full statement in the record.

[The prepared statement of Ms. Sargent follows:]

Testimony

of

Donna Sargent

Director of Health Services

Community Health & Counseling Services, Bangor, Maine

Mr. Chairman, Senator Cohen, and Members of the Committee:

Thank you for the opportunity to provide testimony here today. My name is Donna Sargent; I am a nurse and Director of Health Services at Community Health and Counseling Services (CH &CS) in Bangor, Maine. Our not-for-profit Agency is unique in that it is a community mental health center as well as a Medicare-certified and State-licensed home health agency. In conjunction with Eastern Maine Medical Center, CH&CS also owns New England Home Health Care, which is a private duty nursing agency. We provide services in a four county area of northeastern Maine. This region comprises11,000 square miles and is approximately one and one half times the size of the state of Massachusetts. The area is predominately rural with Bangor, a city of 33,000, being the only M. S. D. (metropolitan statistical district).

In the most recent fiscal year my Department provided 106,318 home health visits and 27,514 hours of homemaker services to 2,659 clients. The services we provide in the home may include nursing, physical therapy, social work, home health aide, homemaker, or, as is often the case, a combination of these services. While we serve all age groups, the vast majority of our current clients are elderly. Eighty-six perce[illegible] over sixty and of these thirty-eight percent (38%) are over eighty years of age. Significant also is the fact that sixty-nine percent (69%) live alone while only twelve percent [illegible] live with a spouse. I am sharing these statistics to give you a sense of the population that we have experience in serving.

In Maine we are proud of the network of community health services that exist across the state. In a recent report published by the National Association for Homecare (N.A.H.C. REPORT No. 512) Maine ranked number forty-six (46) among fifty-one (51) jurisdictions in access to home care and hospice services for its citizens. As the highest ranking was fifty-one (51), it is evident that Maine has one of the highest ratings in the nation. In 1982 the Maine Legislature passed the Home Based Care Act in an attempt to "increase the availability of in-home and community support services for adults with long-term care needs who are at greatest risk of being placed inappropriately in an institutional setting." This program was intended to fill the gap in long-term care services to the chronically ill and disabled caused primarily by restrictions in the traditional funding

sources which pay for home care services (Medicare Title XIII, Medicaid Title XIX, private health insurances, and Social Service Block Grants). For example, there is no Medicare reimbursement for maintenance level care needed by individuals for long periods of time. Medicaid income eligibility for home care is set at a much lower level than eligibility for nursing home care, thereby reducing home care options for individuals under Medicaid. Social Service Block Grant funding for homemaker services is far less than the need. These funding restrictions are often arbitrary, having nothing to do with developing the most appropriate care plan for the individual. Rather these restrictions relate to income levels, homebound status, medical necessity, acuteness of health need, hours of care and length of stay limitations.

The Eastern Agency on Aging (EAA) is responsible for the same geographic area as is covered by my Agency. Over nineteen percent (19.4%) of the total population in this area is over 60 and twenty-five percent (25%) are at or below the poverty line. Therefore, with limited human and fiscal resources, Community Health and Counseling Services (CH & CS) shares the challenge of meeting the needs of this aging population with other service providers in our region. We share with EAA a common goal of maximizing the home care services for the clients we serve and trust in each other's mission and competence. The EAA provides information and referral services to the elder population of our region and has, since 1982, provided case management to the population served under the State funded Home Based Care, Medicaid Waiver, and Medicaid Private Duty Nursing/-Long Term Care Programs. In their case management capacity EAA workers determine eligibility for these three programs and function as a conduit between the client in need of services and the agency(s) providing the services. EAA does not provide in-home services itself and, therein, I believe, lies further explanation for the positive relationship enjoyed in my region of the state between the home health agency and the agency on aging that is sorely lacking in other regions of Maine.

In some regions the area agencies on aging provide in-home service directly, as well as serving as the gate keeper who controls the referral and the purse strings. This is perceived as a conflict of interest by most providers and is in conflict with the Older Americans Act. At the same time the area agencies on aging are excluded from state licensing regulations that govern the delivery of home health services. The area agencies usually provide a less expensive care plan because they can utilize personnel who do not have to meet the same training/ supervision and continuing education requirements as licensed/certified providers. Conflict between the area agencies and the licensed/certified home health providers arises when the cost of the individual plan of care becomes the determining factor in how the service will be delivered. Under these circumstances comparison of the services delivered by area agencies on aging and licensed/certified home health agencies becomes a comparison of apples and oranges, rather than apples and apples.

The state licensed and federally certified home care industry is intensely regulated. These regulations have been designed to protect the most "at risk" homebound population, who are isolated from continuous on-site supervision. These regulations have been developed, based on years of experience and input from providers, to protect the public. If, in fact, these regulatory requirements are critical to the safe and effective delivery of in-home services, then they must apply evenly to everyone providing these services. If they are not necessary, then they must be reexamined and revised so that a true determination can be made as to quality and cost of in-home care and a level playing field can be established for all providers of in-home care.

There is no question that more people of all ages could be cared for at home. Home care, in most cases, offers the best possible quality of life, is most effective, and many times is more cost effective than other types of health care. But we need to recognize the entire continuum of health care. A truly efficient and cost effective system ensures the individual access to care at the point along that continuum that is most appropriate to his needs. The continuum includes as equally valuable components home care, hospitals, physicians, outpatient services, and nursing homes. Each specific component is currently highly developed, thereby offering a tremendous array of health care services to the consumer. However, access is often obstructed due to a poorly developed or non-existent flow among the components.

Picture our current health care system as a castle with many beautiful, but unconnected rooms. Each time an individual wants to move from one room to another he must go outside the castle and attempt to find the right door to reenter. There is no one who knows the layout of the entire castle well enough to guide him to the new door.

My vision for the new health care system is another castle where all the rooms are connected and where one can easily move from one room to the next; here there is someone who knows the ins and outs of this castle well enough to direct each person to where he needs to be.

Each part of the present health care system in this country is so heavily regulated and so separate that it is next to impossible for anyone to truly understand it all. Earlier in my testimony I referred to the Home Based Care Act passed by the Maine Legislature in 1982. While this program has been somewhat effective in gap filling, an early and on-going criticism is that this program has sometimes operated in isolation from other home care services. By failing to coordinate with all service providers, the program established by The Home Based Care Act has fallen short of its goal to maximize the delivery of home care services to those in need and, in some cases, has created duplication of effort and service.

We need to ensure that we do not create costly duplication in service out of frustration with our ability to work within the existing systems. We need to identify why the current systems are not working, what the real barriers to efficient access are, and then, we need to build on what works well and fix only what is broken.

The area agencies on aging have traditionally provided the services of advocacy, information, and referral. I believe the area agencies on aging should also play a key role in directing individuals to the most appropriate place along the healthcare continuum or, as in my analogy, to the right room in the castle. They can do this effectively by contracting with home care networks of community health nurses, rehabilitation therapists, and social workers who have well-developed assessment, case management, coordination and treatment skills. I also believe that once the client is referred to the appropriate component along the continuum, it is essential that the provider, be it the homecare agency, the nursing home, hospital, or physician, has the responsibility and authority to develop the appropriate treatment plan.

I am encouraged by the process in which you are now involved. Such evaluation is critical to any successful planning. Thank you for inviting me to testify. I look forward to helping in any way I can with your efforts to link older Americans to long-term care services.

The CHAIRMAN. We're going to call Frances Hicks.

STATEMENT OF FRANCES M. HICKS, CAREGIVER, ALEXANDRIA, VIRGINIA

Ms. HICKS. Thank you. Good morning, Senator Pryor, and members of the Aging Committee. My name is Frances Hicks, and I reside in Alexandria, Virginia. I'm here today to share with you the story of how my mother, Thelma Haines Vaughan, was aided by the Office for Aging in her efforts to survive and escape an abusive marriage and start her life over with me and my family in Virginia.

She lived with her husband, my father, for 51 years, during which she was continually subjected to verbal and emotional abuse. As she advanced into middle age and their children left home, the abuse gradually became more physical in nature. After several rounds of shock therapy and heavy doses of Thorazine and Artane, which she was on for 20 years, which started in the 1970's, she was diagnosed as having Alzheimer's disease and eventually moved to a nursing home in 1979, as she was becoming more disoriented and distant. We all thought she was succumbing to the symptoms of the disease and that she would eventually die there, but instead she got better and improved in this supportive environment. Her only disabilities at this time were memory loss and confusion, possibly due to the drugs.

In 1989 her husband was forced to remove her from the nursing home because he ran out of money to pay the nursing home bills, and she had to return to a remote, rural area of Texas. I was very concerned that the abusive behavior would return, and my fears came true, for over the next 2½ years, she was periodically subjected to unpredictable angry outbursts, occasional physically abusive episodes, neglect of her health care, and neglect of her personal care needs.

During this period, I was in constant contact by telephone with the Galveston County Office for Aging negotiating care for Mom, which included the following services. First, at their suggestion, she enrolled in a senior citizen program for 2 days a week in order to give him a break from his care-giving duties. Later her time was extended to 4 days a week in a program that was from 9 a.m. to 4 in the afternoon in order to get her away from the home as much as possible.

After the first official report of physical abuse, the Office for Aging began to work with the Texas Adult Protective Services to see if Mom would agree to leave him, or, if not, if they could monitor the situation within the home. A counselor from Family Services had weekly sessions with her in which we could monitor the situation at home. During this time, her personal care needs were neglected, and the Office for Aging arranged for home care workers to go into the home to help her with bathing, dressing, and exercising. Her disability was mostly from arthritis. She couldn't bend or use her legs.

After official and unofficial reports of his increasingly abusive behavior and delays in getting medical attention for her in several emergencies, I and my husband flew with mother to Virginia on Mother's Day, May 10, 1992, in hopes that we could talk her into leaving him permanently. Within 3 weeks, she made the decision

to leave, and we were launched on a year-long effort to restore her health and get her established in a new life. We could never have accomplished these goals without the constant support and direction from the Fairfax County Office for Aging and their special public-private case management program called Elderlink.

Firstly, Elderlink secured—Mom's income was only $54 a month from a Social Security check. Elderlink secured a grant so that she could get her case management fees free. Her emotional health was shaky, as you can expect. She couldn't show emotions, she was apprehensive, and couldn't be left alone. The case manager found a therapist that was experienced in dealing with the elderly and abused women. The case manager helped me to decide on the appropriate level of care needed for her and to select a suitable home to meet her needs and arrange for Medicaid procedures that would complete her admission.

When my father tried to have my mother declared incompetent in order to halt the divorce, the case manager directed us to an excellent geriatric psychiatrist, who gave a telephone deposition verifying her competency for the Texas hearing. He was also instrumental in monitoring her withdrawal from these drugs, which she had been on for 20 years. This took 3 years.

The case manager suggested an elder care program in Alexandria, the Lee Center, which Mom attended 5 days a week up until she entered a nursing home last November. Now she is transported 2 days a week by cabs furnished by the City of Alexandria to attend this program. The friendly center staff has given my mother self-confidence, self-esteem, and community roots in a completely new life. We shall forever be indebted to them for that.

When the emotional and physical demands of caring for Mom became overwhelming for me, the case manager was able to secure a grant for us to receive 4 hours of respite care weekly for Mom.

Lastly, when we needed legal advice for powers of attorney, Medicaid, Social Security, her incompetency hearing, and her divorce, the case manager directed us to attorneys with the Northern Virginia Legal Services. A lawyer with this group continues to help us today in appeals to the Medical Assistance Program of Virginia for Medicaid assistance with nursing home bills during the time period before her divorce was finalized. Healthwise, Mom qualified for Medicaid assistance and SSI disability assistance, but legally she could not get thorough documentation of her financial condition from a hostile spouse, and, therefore, aid was denied.

The Federal Medicaid law is clear in this respect in its intention to supply financial assistance in situations when securing complete documentation is a hardship on the medically needy, but the State of Virginia refuses to recognize her inability to secure this documentation from her spouse.

The support from these programs coordinated by the Office for Aging has literally saved my mother so that now she has a new, happy, secure life. We thank all of them for this gift. I'd like to introduce you to my mom, Thelma Vaughan, and thank you for this opportunity to share our story with you today.

[The prepared statement of Ms. Hicks follows:]

TESTIMONY BEFORE THE SENATE SPECIAL COMMITTEE ON AGING

Senator David Pryor, Chairman

June 8, 1993

Good morning Senator Pryor and members of the Aging Committee. My name is Frances Hicks and I reside in Alexandria, Virginia and I am here today to share with you the story of how my mother, Thelma Haines Vaughan, was aided by the Office for Aging in her efforts to survive and escape an abusive marriage and start her life over with me and my family in Virginia.

She lived with her husband, my father, for 51 years during which she was continually subjected to verbal and emotional abuse by him. As she advanced into middle age and their children left home, the abuse gradually became more physical during his unpredictable outbursts of anger and she went into a deep depression. After several rounds of shock therapy and drug treatment with heavy doses of Thorazine and Artane, she was diagnosed as having Altzimer's disease in the mid-1970's. She was placed in a nursing home in 1979 as she was becoming more disoriented and distant and he continued to neglect her care; we all thought she was succumbing to the symptoms of the disease and that she would eventually die there, but she didn't , she improved once she was in a safe supportive environment. Her only handicaps were some memory loss and confusion, possibly from the effects of the drugs.

In 1989, her husband ran out of the money needed to pay the nursing home bills and she had to return to live with him in a remote, rural area of Texas. I became very concerned that his abusive behavior would return and her emotional condition would worsen. My fears came true, for over the next two and a half years, she was periodically subjected to angry outbursts with threats and harassment, occasional physically abusive episodes, neglect of her health care, and inattention to her personal care needs. During this period I was in constant contact by telephone, long distance from my home in Virginia, with the Office for Aging (hereafter referred to the OFA) in Galveston, Texas negotiating care for Mom and monitoring the home situation as best as possible.

First they suggested that I enroll Mom in a local Senior Center program for two days a week in order to give him a break from his caregiving duties, but that didn't seem to curb the hostilities at home. Then after the first official report of physical abuse was reported, the OFA began to work with the Texas Adult Protective Services caseworker to see if she would agree to leave him or, if not, to monitor and try to improve the family situation.

During one of my periodic visits to Texas, the OFA helped me arrange for Mom to attend an elder care program four days a week, from 9 AM to 4 PM, in order to get her away from home as much as possible until a permanent solution could be found for this problem. The driver of the van for the OFA provided friendship and support to Mom during their weekday two-hour rides back and forth to the program, the OFA staff gave me long distance advice on options for Mom and occasional emotional support when I became frantic about her safety.

A counselor from Family Services talked with Mom weekly to monitor the home situation with her husband, and, with Mom's permission, she shared this information with me by telephone and with the Elder Care Center and Office for Aging Staff. During this time the Elder Care Center staff reported that Mom's personal care needs were being neglected, so the OFA staff helped arrange for home care workers to come once a day to help her bathe, dress and exercise with her. At this time her disabilities included difficulty in movement due to Arthritis in her back and legs, incontinence, and confusion and occasional short term memory loss -- she could not be left alone.

After reports from Mom, family , home health aides and the adult protective authorities of his increasingly abusive behavior and several instances of his delay in getting medical attention for some life-threatening emergencies with her, I and my husband felt compelled to take action to get her out of this life threatening situation. On Mother's Day, May 10, 1992, we flew with Mother to Virginia with the hopes that we could talk her into leaving him permanently; within

three weeks she had decided not to go back and we were launched on a year-long effort to restore her health and get her established in a new life. We could never have accomplished these goals without the constant support and direction from the Fairfax County Office for Aging and their special public-private program of case management, Elderlink. This case management program which is jointly funded by the Office for Aging, ANOVA Health Systems, and the Altzimer's Association helped secure the following services:

* Because Mom only had an income of $54 per month from Social Security, Elderlink secured a grant so that her casemanagement services were free.

* Her emotional health was shaky - she couldn't show emotions, she was apprehensive all the time and couldn't be left alone, the casemanager found a therapist that was experienced both in dealing with the elderly and abused women.

* The casemanager, working with staff from the Health Department, helped me to decide on the appropriate level of care needed for Mom, select an appropriate home that would meet her needs, arranged the Medicaid Needs Assessment, and helped to steer us through the maize of arrangements to be made for her move.

* When my father tried to have Mom declared incompetent in order to halt the divorce, the casemanager directed us to an excellent geriatric psychiatrist who gave a telephone deposition for the Texas hearing. His testimony to the fact of her competency and the mind-altering effects of the drugs that she had been on for 20 years literally turned the case around in her favor.

* The casemanager suggested an elder care program at the Alexandria Lee Center which she attended 5 days a week up until entering a nursing home last November. Now she attends two days a week; cabs are provided by a special transportation program in the city of Alexandria for elderly and indigent persons. The friendly staff at the center has given my mother self-confidence, self-esteem, and community roots in a completely new life --- we shall forever be indebted to them for that.

* When the emotional and physical responsibilities of caring for Mom became overwhelming, the casemanger offered comforting advice and was able to secure a grant for us to receive respite care in our home; four hours every weekend a trained respite care worker would stay with Mom while my husband and I would go out. Ordinarily this worker would cost $13.50 per hour, but the grant paid for most of this fee.

* Lastly, when we needed legal advice for powers of attorney documents, Medicaid, Social Security, and her incompetency hearing and divorce, the casemanger directed us to attorneys with the Northern Virginia Legal Services. A lawyer with this group continues to help us in appeals to the Medical Assistance Program of Virginia for Medicaid assistance for nursing home bills during the time period before her divorce was final in March. Healthwise, Mom qualified for Medicaid Assistance for nursing home care since last August and SSI disability assistance from May, 1992, because of her disability and low income, under $115.00 per month, but, legally, she was unable to get thorough documentation of her financial condition, therefore aide was denied. Federal Medicaid Law is clear in its intention to supply financial assistance in situations when complete documentation is unavailable, but the state of Virginia has never applied these provisions of the law and refuses to recognize her inability to secure this documentation from her hostile spouse.

The support from these agencies working hand-in-hand in an unbelievably cooperative network with the Office for Aging has literally saved my Mother, so that now she has a new, happy, secure life at the "young" age of seventy-six --- we thank all of them for this gift. I'd now like to introduce you to my Mom, Thelma Vaughan and thank you for this opportunity to share our story with you today.

Frances M. Hicks
1705 Hackamore Lane, Alexandria, VA 22308

The CHAIRMAN. Thank you very, very much. We appreciate this so much. It was a very touching and human story. Many Americans are going through very similar situations, Ms. Hicks, and you have been very courageous and loving with your mother, and we appreciate this very much.

Senator Grassley, do you have a question?

Senator GRASSLEY. One question for Ms. Eubank, and I understand she's from Arkansas.

The CHAIRMAN. That's right.

Senator GRASSLEY. This is probably more of a philosophical discussion that you probably get into about the role of the area agencies, whether or not they'd be in a coordinating role or a direct services role, and you made reference to direct services in your statement. As you know, there are some who believe that the network should not provide direct services, but should confine itself to information and referral, case management, and contracting for specific services.

Could you elaborate a bit on your view of the appropriate relationship between direct and other coordinating-type services? This could be, I think, an important question as we deal with long-term health care and the consequences that this approach has on long-term health care.

Ms. EUBANK. We provide services directly in the in-home area, specifically Medicaid and Medicare. We don't provide any in Older Americans Act programs. I think it's a real important issue, and I think area agencies could function in either role, especially in the in-home area as an in-home provider or as a case management coordination kind of role. I think ideally the two should be separated.

From a philosophical standpoint, I think that probably in some small States that might not be possible. It might have to be some combination. But I think ideally you would have area agencies providing one or the other role.

Senator GRASSLEY. Okay. But it's generally your view that in most cases they should not provide both direct and coordinating services. Is that your statement, your conclusion?

Ms. EUBANK. In the in-home area, in our State we don't provide the function where we decide what services are being purchased, so, therefore, it's not a conflict for us to provide some coordination in addition to some direct service delivery. If we were ever to be in a role where we were to decide what services the client actually received, then I think it would be a conflict. I truly think the area agencies could function in either role.

Senator GRASSLEY. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Grassley.

By the way, Senator Grassley has been one of the most faithful and loyal members of this Committee for as long as I've been on it, and it's been such a pleasure working with him as with all of the Members of this Committee.

Let me assure our witnesses this morning that this Committee is not a Republican or a Democrat Committee. We don't have votes on party line issues, and we really try to get down to the issues of what matters to the elderly people of our country, and we're so very grateful to all of you for coming today and sharing with us your experiences.

I want to ask you a general question. We're about to come forward now with a health care plan from the White House. Let's just engage in a little bit of fantasy here for a second. Assume for a moment that you were going to have lunch with President and Mrs. Clinton, and you had the opportunity to say, "Okay, Mr. President, Mrs. Clinton, we've been out there in the trenches delivering health care and dealing with the problems of the elderly and delivering these services day by day. Here is what we recommend to you to do in long-term care."

What would you say, Ms. Hicks? What would you have as a comment there to the President and our First Lady?

Ms. HICKS. I think that I've had some experience around nursing homes lately, and I think that they need to be more aware that the elderly population is not monolithic, that elderly women are the majority of these populations in nursing homes, and that they have special needs. I think that the nursing homes ought to be made more friendly, because, for instance, my mother was telling me that one of the residents, her good friend, died the other day, and they asked all the residents to stay in their rooms while the body was being taken out, and this is a friend. I mean, this is someone that she visited with all the time, and they don't get a chance to really mourn and have some sort of goodbye. I think it ought to be more humane.

The CHAIRMAN. Thank you. You're a very articulate spokesman, I might say.

Elaine, what would you suggest?

Ms. EUBANK. That older people need choices and options on how they receive services, more than they have now. Because right now you have to fit into—in Arkansas, anyway—into the Medicaid category to have an option, because there's no other reimbursement source for in-home and community services, other than the Older Americans Act money, which is very limited.

The CHAIRMAN. Donna.

Ms. SARGENT. I agree also that the options need to be there, and a system that will allow access to wherever the individual needs to be along the entire continuum of care I think is very important.

The CHAIRMAN. Thank you.

We want to express our gratitude to the three of you and all of our panelists this morning. Thank you very, very much.

Our hearing is adjourned.

[Whereupon, at 11:38 a.m., the Committee adjourned, to reconvene at the call of the Chair.]

APPENDIX

STATEMENT

of the

American Federation of Home Health Agencies

Submitted by:

Ann B. Howard
Executive Director

The Aging Network: Linking Older Americans to Home and Community-Based Services

Long-Term Care and Health Care Reform The Role of Case Management

The American Federation of Home Health Agencies (AFHHA), a national association representing Medicare-participating home health agencies, is concerned that providers may be excluded from a case management role in long term care under a reformed health care system.

We believe that the cost of home health and community-based services should not be increased needlessly by the imposition of a layer of bureaucracy in the form of third-party case managers. Home health agencies routinely provide case management services in the private sector, and are required by law to coordinate all care received by Medicare patients regardless of source (42 CFR 484.14(g) and 484.18(a)).

At an open forum of the President's Task Force on National Health Care Reform on March 29, participants in the long term care panel were asked what incremental steps toward long term care should be taken first. Several panelists suggested creation of the case management component. AFHHA believes that it is not necessary to create a new structure since there already is a highly effective case management system which includes providers as case managers of long term care services.

It is our belief that only certain individuals need to be case managed. Those who can benefit from case management include individuals with health and social service needs which are predicted to be costly, medically complex cases, and cases where there are multiple service providers. Provision of full case management services to all consumers, regardless of the need, drains away funds which should be expended for direct patient services.

A Recommendation for the Design of the Case Management Component of Health Care Reform

Health care reform legislation should permit any and all case management entities to participate in any long term care or public program, provided they meet established standards of professional performance and have the capacity to perform interdisciplinary assessments.

In designing the case management component of a reformed health care system, the Congress and the Administration should explore several alternative methods to (1) address potential conflicts of interest, (2) assure client access, (3) control costs, and (4) assure quality. *We urge that the Congress and the Administration not take the extreme measure of excluding health care providers who are currently familiar with and providing assessment and case management, in accordance with their legal mandate.* Potential concerns could be addressed by case management designs which:

- Require all agencies that otherwise meet case management standards to *refer no more than a designated percent of all business to related agencies or programs.*

- Require case management agencies to solicit bids for services so that in areas large enough to have multiple service providers there is a roster of providers who have met designated service, professional, and price criteria. These bids could be handled by the case management agencies or by some designated public agency. In areas with single providers, some other arrangements could be made.

- Allow payments to be made on an aggregate or capitated basis, with appropriate incentives for service substitution and quality maintenance.

- Establish performance monitoring criteria.

- Require that eligibility for the program be determined by a public entity or a designated private body, while the case management agency would develop the plan of care with the client and family.

- Establish uniform guidelines to help case managers apportion services and to ensure equitable distribution of services among clients with similar conditions and circumstances.

Health Care Providers as Case Managers

The majority of the organized, recognized, and large scale case management agencies around the nation are also providers of a comprehensive range of services, including hospital, nursing home, home health care, and community-based long-term care.

Unfortunately, the vast majority of agencies that now provide long-term care case management are barred from doing so under the OBRA 1990 case managed Medicaid home and community-based frail elderly program, which stipulates that case management entities must be public or nonprofit and may not have any direct or indirect relationship with providers of nursing home or home care services. *Congress and the Administration should not duplicate this exclusive OBRA 1990 case management model, which adds a layer of bureaucracy onto the existing mandated provider case management system.* A number of models of case management should be permitted, including third party models such as the Area Agencies on Aging and independent case management programs, in addition to provider case management, so long as they meet all Federal requirements.

Established programs combining service provision and case management which are excluded from a case management role under the frail elderly Medicaid program include: the On Lok program in San Francisco which provides community services as an alternative to nursing home care, Nursing Home Without Walls, New York State's Long Term Home Health Care Program, and Social Health Maintenance Organizations, which provide long term care services to a chronic population in an HMO setting.

AFHHA is a participant in the National Case Management Caucus, which was formed in 1992 to address the issue of provider case management in a reformed health care system. A position paper developed by the Caucus follows.

Health Care Reform
The Role of Provider Case Management

The National Case Management Caucus was formed in 1992 by a broad coalition of health care providers, including representatives of hospice, home health, hospital, nursing home, nursing, and durable medical equipment organizations, who believe that case management provisions in legislation to reform the nation's health care system and in long term care legislation must preserve the case management role already being performed by health care providers.

What is Case Management ?

The purpose of case management is to provide an efficient and cost effective means of organizing and delivering health care and social services to qualified individuals. Case management can have a gatekeeping mechanism, and advocacy function, or be a diagnostic and prescriptive service. Case management may encompass any or all of the following components:

- gatekeeping and eligibility determination
- assessment of needs, including medical, social, and psychological
- level of care determination
- care plan development
- direct service provision of designation of service providers
- client advocacy
- coordination of health care and social services from all providers
- budget planning
- monitoring delivery and quality
- family support

Certified home health agencies are actually funded through Medicare for case management services under a new benefit -- skilled management of the care plan.

Who Needs Case Management Services ?

Only certain individuals should be case managed. Aside from some eligibility determination, case mangement is not necessary for all. The following are some of the characteristics of those who can benefit from case mangement:

- Have health and social service needs which are predicted to be costly
- are medically complex cases, such as high risk pregnancy, premature birth, head and spinal cord injury, AIDS, and organ transplant
- are in need of multiple service providers
- have chronic disabilities
- are mentally impaired
- are unable to perform some or all activities of daily living
- are at risk of institutionalization
- have insufficient family support systems
- have needs which are prone to change frequently

The following are examples of established programs combining service provisions and case management which are excluded from a case management role under the frail elderly Medicaid program and by a number of current health care reform and long term care proposals:

- On Lok: based in San Francisco, originally paid under Medicare and Medicaid waivers to provide community services as an alternative to nursing home care, and currently a capitated model.

- MSSP (Multi Service Senior Program): A California Medicaid (MediCal) program with public and private nonprofit agencies participating.

- S/HMO (Social Health Maintenance Organizations): providing long term care services to a chronic population in an HMO setting.

- Nursing Home Without Walls (New York State Long Term Home Health Care Program): a network of home care provider agencies with a service cap; related to nursing home costs.

- Medicare Alzheimer's Disease Demonstration: providing community services and case management to Alzheimer's patients and families with a monthly service cap; five of eight sites are providers.

- Medicaid Channeling Project at the Miami Jewish Home and Hospital for the Aged: A Channeling model to provide services to a Medicaid population deemed by the state to be nursing home eligible; paid a per diem all-inclusive rate per patient day.

- Huntington Memorial Hospital, Pasadena, CA: a Robert Wood Johnson Foundation site for case managed community long term care insurance (with UNUM, a Maine based disability insurer), a Multi Service Senior Program site, a private service provider.

- Benjamin Rose Institute, Cleveland, OH: a case mangement and provider agency operating insurance, employer, and grant-paid programs.

- Connecticut Home Care Coalition Demonstration Project: through the State Department of Aging's Program for Independent Living; has demonstrated that service providers can effectively manage client care without the cost of a third party case manager.

In designing health reform legislation, Congress should act to ensure that the above programs, as well as other programs developed by providers mandated by law to perform the case management function, may continue to serve in the capacity of case managers. This will serve to:

- Target case management only to those who require such services;

- limit unnecessary expenditures for case management services;

- prevent the creation of an unneeded layer of bureaucracy;

- prevent the bottlenecks to care which occur when there is a single model of entry into and management of the health care system; and

- utilize the skills of experienced health care professionals who are monitored on a regular basis for the quality of the care they provide, including their case management services.

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How Should Congress Design Case Management Programs ?

Congress should permit any and all case mangement entities to participate in any public program, provided they meet established standards of professional performance and have the capacity to perform interdiscinplinary assessments.

In designing the case management component of health reform legislation or long term care legislation, Congress should explore several alternative methods to (1) address potential conflicts of interest, (2) assure client access, (3) control costs, and (4) assure quality. Congress should not take the extreme measure of excluding health care providers who are currently familiar with and providing assessment and case management, in accordance with their legal mandate. Congressional concerns could be addressed by case management designs which:

- Require all agencies that otherwise meet case management standards to refer no more than a designated percent of all business to related agencies or programs.

- Require case management agencies to solicit bids for services so that in areas large enough to have multiple service providers there is a roster of providers who have met designated service, professional, and price criteria. These bids could be handled by the case manage ment agencies or by some designated public agency. In areas with single providers, some other arrangements could be made.

- Allow payments to be made on an aggregate or captitated basis, with appropriate incentives for service substitution and quality maintenance.

- Establish performance monitoring criteria.

- Require that eligibility for the program be determined by a public entity or a designated private body, while the case management agency would develop the plan of care with the client and family.

- Establish uniform guidelines to help case managers apportion services and to ensure equitable distribution of services among clients with similar conditions and circumstances.

Should Health Care Legislation Permit Case Management by Health Care Providers ?

The majority of the organized, recognized, and large scale case management agencies around the nation are also providers of a comprehensive range of services, from hospital to nursing home to community-based long term care to home health care.

Unfortunately, the vast majority of agencies that now provide long term care case management are barred from doing so under the OBRA 1990 case managed Medicaid home and community based frail elderly program, and would also exclude under a number of current legislative proposals which define eligible case mangement partly by exclusion: agencies must be public or nonprofit and may not have any direct or indirect financial relationship with providers of nursing home or home services. Congress should not duplicate the exclusive OBRA 1990 case management model, which adds a layer of bureaucracy onto the exsisting mandated provider case management systems. The National Case Management Caucus believes that a number of models of case management should be permitted, including third party models such as the Area Agencies on Aging and independent case mangement programs, in addition to provider case management, so long as they meet all Federal requirements.

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