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FACES OF AGING: PERSONAL STRUGGLES TO CONFRONT THE LONG-TERM CARE CRISIS

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

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FACES OF AGING: PERSONAL STRUGGLES TO CONFRONT THE LONG-TERM CARE CRISIS

THURSDAY, SEPTEMBER 26, 2002

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

The committee convened, pursuant to notice, at 10:05 a.m., in room SD–628, Dirksen Senate Office Building, Hon. John Breaux (chairman of the committee) presiding.

Present: Senators Breaux, Wyden, Lincoln, Stabenow, and Craig.

OPENING STATEMENT SENATOR JOHN BREAUX, CHAIRMAN

The CHAIRMAN. The committee will please come to order. Our committee has the responsibility to look forward and see that our country is prepared to handle the long-term care needs of the pending age wave of some 77 million baby boomers. That is why we have devoted some 13 previous hearings to various aspects of long-term care. Over the course of our hearings, we have learned a great deal of important information from our witnesses, but two themes, I think, have been heard over and over again.

The first is that the demand for long-term care services far exceeds the available services that are there. The average person that needs long-term care assistance must depend on family for everyday support to live independently.

The second recurring theme is that there is an institutional bias. Most Medicaid dollars are spent on institutional care. It is an entitlement to go into a nursing home, but you need a waiver to stay in your own home. This policy is upside down.

Today, we want to explore the personal side of the long-term care issue. We want to put some names and faces on these issues. What is it like to try and navigate through such an inefficient and outdated long-term care system? Will you receive better services if you live in Oregon rather than in Louisiana? Where do you begin your search? Who do you call? What do we need to know?

While we cannot overhaul the long-term care system overnight and offer everyone the services that they need, we can offer families some assistance in their search for long-term care. This card lists resources on one side that you can either access with a telephone call or a computer website. The other side lists steps to take and basic questions that you need to ask in order to find care for your loved one. Hopefully, this will be helpful to people who are facing or will soon be facing a long-term care situation in their family.

I would like to recognize our good friend and colleague, Senator Stabenow from Michigan, if she has any comments on this issue she would like to make.

OPENING STATEMENT OF SENATOR DEBBIE STABENOW

Senator STABENOW. Thank you. Good morning, Mr. Chairman, and thank you to those who are sharing information today. This is such a critical issue.

I would first ask that my statement be submitted for the record.

The CHAIRMAN. Without objection, it will be made part of the record.

Senator STABENOW. Thank you. We have so many challenges in front of us for families and I think it is important that we focus on how this issue affects patients in their homes, and directly affects their families, and loved ones.

While there are many, many challenges, associated with long-term care providers in Michigan are trying to be creative. Michigan office of services to Aging has developed something called miseniors.net, which is a comprehensive portal to long-term care services for seniors. Adult children can research their options, connect with human services workers and so on; and so they are trying to be helpful by bringing together information.

But I know that all of us either have faced in our own family or will face the challenges that come with a parent, a spouse, or a loved one who needs some kind of long-term care/and the challenges of wanting to keep them at home as long as possible. We should receive support to do that. We need a system that can help families, keep loved ones at home but also have out-of-home care available.

This is a real challenge and I appreciate your ongoing focus on this. Living longer is a good thing, but the challenge of living longer and what that brings for us will become an even more important issue as we move forward, so thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

[The prepared statement of Senator Stabenow follows along with a prepared statement of Senator Larry Craig:]

PREPARED STATEMENT OF SENATOR DEBBIE STABENOW

I want to thank Chairman Breaux and Senator Craig for holding this hearing. Looking at the broad systemic challenges of financing and delivering long-term care is essential to crafting a better approach for America's seniors and disabled citizens. However, too often we get caught up in technical policy details and not pay enough attention to the daily experiences of men and women seeking long-term care for their loved ones. Understanding their plight is also essential for good policy making.

As Senators, we have the luxury of information resources. Our staff, the Congressional Research Service, our state agencies and academia all help us understand the complicated web of financing and delivery systems that make up long-term care. Who helps the young mother with a busy home and career navigate the complexities of securing care for her aging parents? What about the elderly man, struggling with his own limitations, who needs help caring for his wife who can no longer feed or clothe herself?

Like other states, Michigan's long-term care system is not easy for consumers to steer: there is no single point of entry, no early intervention strategies, few choices for care, and an emphasis on institutionalization over independent living.

Phyllis Moga of Grand Rapids, Michigan is all too familiar with the challenges of the system. Her mother suffered from Alzheimer's and when it became clear that she could no longer be left alone, Ms. Moga and her three sisters turned to private in-home aids for help. They knew that their mother would not be eligible for Medic-

aid, and therefore had no access to public assistance with home care. She did not qualify for the Medicare home health benefit because her condition was not acute.

They put ads in the newspaper looking for home health aids to stay with their mother during the day while they could not be there. They hired one after another, and inevitably, the aids would leave their mother alone or not show up at all.

Although the private care was inadequate, Ms. Moga and her sisters spent so much money on it that her mother soon qualified for Medicaid. Unfortunately, they heard that it was next to impossible to secure Medicaid assistance for home care because there were only limited slots. So, while her mother could have thrived with some help at home, Ms. Moga and her sisters placed her in a nursing home.

They had no help in finding the home as they did not know about the Long-term Care Ombudsman nor the Department of Consumer and Industry Services. They chose the home based on a tour of the facility and the assurance of that it complied with state regulations.

Ms. Moga's mother experienced three years of abuse and humiliation at the home, including being found in bed with a broken hip and bruises on her arms. Not knowing where to turn, Ms. Moga became a member of the Family Council, an intermediary between the nursing home administrators and families of those housed there. She fought tirelessly to hold them accountable for the abuse, secure additional staff and promote training within the facility.

Three months ago, Ms. Moga's mother was rushed to the hospital by the nursing home suffering from a bowel complication that could have been avoided with proper care. She passed away upon arrival at the emergency room.

Shortly before her mother's death, Ms. Moga met someone from Citizens for Better Care, also known as CBC, who attended a meeting of the Family Council. CBC helped her file a complaint with the Michigan Department of Consumer and Industry Affairs. She just recently received a letter saying the state could not determine that the nursing home did anything wrong.

Needless to say, Ms. Moga is devastated by what happened to her mother. She believes strongly that had she known more about the system and the resources available to help her, things would have been different.

It is not all doom and gloom in Michigan. Long term care providers are being creative in their approaches to fixing the problems. One impressive innovation is the creation of MISeniors.net, which is a comprehensive portal to long-term care for seniors, adult children researching their options and human service workers in the field of aging. It provides a wealth of information and serves as a much needed starting point.

I look forward to continuing to tackle the many challenges we face around the country in providing quality care to our seniors. It is very important that we share stories today, like Mrs. Moga's story I have shared with you, to understand how finding long term care solutions is a real, daily struggle for families everywhere. I hope that this hearing helps this committee focus its efforts to help families so that tragedies like the Moga family experience can be prevented in the future.

PREPARED STATEMENT OF SENATOR LARRY CRAIG

Good morning. I would like to thank the Chairman for holding this important hearing today. I would also like to thank all of the witnesses here today for agreeing to testify before this committee about our nation's long-term care system.

This hearing is important because we need to focus the nation's attention on long-term care reform. Our long-term care system is lagging behind the need as Americans are living longer. These problems will only become worse as 77 million baby boomers reach retirement age.

One of the biggest problems facing our long-term care system is access to information. Services and funding available vary from state to state, making an individuals' search for appropriate care extremely complicated. Many Americans don't know what services are available to them, how to choose the services, how much they cost, and where they can go for financial help. Americans need to be armed with the best information available in order to make important decisions regarding complex long-term care programs.

For example, in my state of Idaho, we have one toll free number for seniors. Seniors or their families can call one number and the call is automatically transferred to the Area Agency in their community. This helps to eliminate some of the confusion and gives seniors one place to go for information.

Throughout the process of reform, we need to look at devising methods to finance our long-term care system. We should also make it a priority to help Americans plan for their future. For example, the federal government has already started to make

long-term care insurance an option for their employees. Information about long-term care insurance and other options to help finance care should be made readily available.

All Americans should be informed and should have access to long-term care services. They should also be provided with appropriate information in order to make educated family decisions as to what services are best suited for them. It is very important that we find solutions to the problems plaguing the long-term care system to that we may continue to depend on quality care to help take care of our loved ones.

I'd like to thank each of witnesses for being here today and for sharing their insights into this complex problem. I look forward to hearing your testimony.

The CHAIRMAN. The card that I referred to, of course, in my statement is the blue card that we have up here which the committee has prepared which is sort of a guide for people who are initially approaching the question of accessing long-term care at home. Of course, as I indicated, the first part of the card lists all the free services that are available to help you in finding how to determine what is best in terms of long-term care for your loved ones. Who can you call to get the information that you need? A lot of people simply do not know where to start. Our card kind of gives them a good starting point.

A second part of the card, on the back, gives them helpful suggestions about how they should go about making these decisions and also the type of information that you are going to need before you start seeking ways to provide long-term care, so you can have everything in order as you proceed down this somewhat complicated path to finding out what is best for you and your family.

We are delighted to have our panel of witnesses this morning. We will start with Ms. Kathy Allen, who is Director of Health Care, Medicaid, and Private Health Insurance Issues over at the General Accounting Office, who works so closely with our committee. I understand she is going to discuss the recent GAO report that has been released specifically for this hearing, in which we have asked them to look at sort of the status of long-term care services in four States, my own State of Louisiana, Kansas, New York, and Oregon.

Ms. Allen, we thank you for being with us. You may proceed.

STATEMENT OF KATHRYN G. ALLEN, DIRECTOR, HEALTH CARE, MEDICAID, AND PRIVATE HEALTH INSURANCE ISSUES, UNITED STATES GENERAL ACCOUNTING OFFICE

Ms. ALLEN. Thank you, Mr. Chairman, Senator Stabenow. It is a pleasure to be here today as you continue this series of hearings on the public sector role that will help meet the long-term care needs of America's seniors.

Long-term care spending, as you noted, is already a substantial part of Federal and State budgets and the impending tidal wave of the baby boom generation is only going to continue to increase demand for these services. Despite the fact that the bulk of current long-term care spending is for institutional care, the greatest interest and demand will undoubtedly be increasingly for in-home and community-based care that will enable individuals in the face of declining health and independence to remain in their homes and communities as long as possible.

This morning, I would like to focus my remarks on highlights of the report that we completed at your request, Mr. Chairman, on

coverage of long-term care in home and community-based settings. We focused specifically on Medicaid because it is currently the largest payer for long-term care services nationwide.

We wanted to give this work a real-life flavor, and so we approached it from the point of view of an elderly person with a very specific set of needs who is seeking care directly from a Medicaid case manager. Now, obviously, there are other avenues that one could pursue for needed services, and I trust that other witnesses today will be able to address some of those other avenues.

For our work, however, we developed profiles of two hypothetical elderly persons, an 86-year-old wheelchair-bound woman with debilitating arthritis, and a 70-year-old man with moderate Alzheimer's disease who is recovering from a hip fracture. These individuals would be immediately eligible for nursing home care financed through Medicaid, but they would prefer to remain at home. For each of these two hypothetical persons, we developed three scenarios where they had varying levels of informal care available from their family. We then asked four Medicaid case managers in each of the four States you mentioned to develop care plans for the scenarios.

To illustrate our findings across the scenarios, let me focus on just one of them, the 86-year-old woman, who we named Abby, who has physical limitations due to debilitating arthritis and type II diabetes. This is a very typical situation that I am sure many of us can relate to. Abby is wheelchair-bound, has developed a pressure sore as a result, and she has some degree of difficulty with all activities of daily living, including eating, dressing, bathing, using the toilet, and getting in and out of her wheelchair. She needs help to take her medications and to check her glucose levels daily to monitor her diabetes.

Her husband, who had been her primary caregiver, has recently died. Abby has now moved in with her daughter, but she herself is overwhelmed by her new caregiving responsibilities for her mother, in addition to the fact that she is caring full-time for her own grandchild.

Across the 16 care plans that we identified, all but one of the case managers offered Abby services that would help her stay at home. But the number of hours of in-home care varied considerably across these case managers, ranging from 4.5 hours in one situation to 40 hours in another. To augment this care, several case managers also offered her adult day care, ranging from eight to 24 hours a week. This adult day care would provide her with additional hours of care and would also provide her daughter with some respite.

Case managers also offered Abby, to varying degrees, additional services, such as home health care, sometimes financed by Medicaid, sometimes by Medicare; home-delivered meals; assistive devices for the bathtub, such as a grab bar or transfer seat; emergency personal call device; volunteer senior companionship; and family caregiver counseling or respite to help her daughter. Some of these services were covered by Medicaid, while in other cases they were available through other Federal, State, or local programs.

The care plans that case managers developed in response to our scenarios reflected what would be offered to individuals assuming no constraints on the number of individuals who they could serve. But in reality, we found that in some cases there were waiting lists, because the services were being provided through Medicaid waivers, that would preclude these people from being able to immediately obtain the home or community-based services paid for by Medicaid.

In general, across the various scenarios we explored, we found that case managers developed care plans that relied largely on in-home services. In the few cases where they recommended that Abby or Brian move to a nursing home or other residential care setting, it was almost always because he or she was living alone, had no family or other informal support available, and the case manager was concerned that the individual could not be safe at home.

In the majority of cases where in-home care was offered, we found there was considerable variation in the number of hours offered and in the extent to which other locally available non-Medicaid services would be factored into the care plan.

In conclusion, Mr. Chairman, we found that the same individual, who is Medicaid-eligible, who is elderly, with a certain set of disabling conditions, care needs, and family support would find very different care plans in terms of the type and volume of services that would be offered. These differences arise, in part, from decisions that States have made in how they design their long-term care programs and the amount of resources they are able to devote to them. But these differences also a rise, very significantly from a lack of consensus as to what services are needed to compensate for disabilities and what balance should exist between publicly available services and that which the family can provide.

Mr. Chairman, this concludes my prepared remarks.

The CHAIRMAN. Thank you very much, Ms. Allen. We will have some questions, of course, for you.

[The prepared statement of Ms. Allen follows:]

United States General Accounting Office

GAO

Testimony

Before the Special Committee on Aging, U.S. Senate

For Release on Delivery
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LONG-TERM CARE

Elderly Individuals Could Find Significant Variation in the Availability of Medicaid Home and Community Services

Statement of Kathryn G. Allen
Director, Health Care—Medicaid
and Private Health Insurance Issues

GAO-02-1131T

Mr. Chairman and Members of the Committee:

I am pleased to be here today as you continue to explore issues that confront many elderly Americans seeking long-term care services, with today's focus on care options that can allow elderly individuals—as they face declining health and independence—to remain in their homes and communities as long as possible. This Committee has held a series of hearings this year examining the current provision of long-term care and considering the role that the public sector should play in assuring that long-term care needs will be met for the impending surge of the baby boom generation. The availability of home and community-based care is an important aspect of the overall long-term care spectrum.

As the Comptroller General testified before this Committee in March, the aging baby boom generation is anticipated to greatly expand the demand for long-term care services, which could result in spending for long-term care for the elderly nearly quadrupling by 2050.[1] This growing demand for long-term care will exert increased pressure on federal and state budgets since long-term care relies heavily on financing by public payers, particularly Medicaid, which is currently the largest payer for long-term care services. Nursing home care traditionally has accounted for most Medicaid long-term care expenditures, but the high costs of such care and many individuals' preferences to remain in their own homes has led states to expand their Medicaid programs to provide coverage of home and community-based long-term care services.

States have considerable discretion within their Medicaid programs to decide who may be eligible for home and community-based care and what services to cover. Most home and community-based services—including in-home assistance with activities of daily living, such as bathing or eating, or community-based options, such as adult day care or assisted living facilities—are optional elements of state Medicaid programs. Local case managers, who screen Medicaid-eligible individuals to determine what services they qualify for, also often have discretion to customize care plans based on an individual's needs, preferences, and the availability of care services, including unpaid care provided by family members or other informal caregivers.

[1]See U.S. General Accounting Office, *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*, GAO-02-544T (Washington, D.C.: Mar. 21, 2002).

My remarks will summarize findings of a report that we are releasing today that examines four geographically diverse states—Kansas, Louisiana, New York, and Oregon—that varied in their coverage of Medicaid home and community-based services.[2] At your request, we examined how these states' coverage policies affected long-term care services available to elderly individuals needing care. We focused on three specific issues: (1) the extent to which home and community-based services were available for Medicaid-eligible elderly, (2) services that local case managers would offer to two hypothetical elderly individuals based on the levels of unpaid informal care provided by family members, and (3) the extent to which care offered to the same individual with the same level of informal support varied among the selected states.

The cornerstone of our work was the development of vignettes for two hypothetical elderly persons—an 86-year-old woman with debilitating arthritis and a 70-year old man with moderate Alzheimer's disease. For each of these hypothetical individuals, we developed three scenarios where the individuals had varying levels of informal care available from their families and preferred to remain at home as long as possible. We then asked four Medicaid case managers in each of the four states to develop care plans for each scenario.[3]

In summary, we found that a Medicaid-eligible elderly individual with the same disabling conditions, care needs, and availability of informal family support could find significant differences in the type and intensity of home and community-based services that would be offered for his or her care. These differences were due in part to the very nature of long-term care needs—which can involve physical or cognitive disabling conditions—and the lack of a consensus as to what services are needed to compensate for these disabilities and what balance should exist between publicly available and family-provided services. The differences in care plans were also due to decisions that states have made in designing their Medicaid long-term care programs and the resources devoted to them. The case managers we contacted did offer, in general, care plans that relied largely on in-home services rather than other residential care settings. However, there was

[2]U.S. General Accounting Office, *Long-Term Care: Availability of Medicaid Home and Community Services for Elderly Individuals Varies Considerably*, GAO-02-1121 (Washington, D.C.: Sept. 26, 2002).

[3]In each state, we selected two case managers in a county with a small town (less than 15,000 people) and two in a county with a large city (at least 250,000 people).

considerable variation in the extent of in-home services offered. For example, for our hypothetical 86-year-old woman with debilitating arthritis, case managers recommended from 4.5 hours per week to 40 hours per week of in-home assistance to supplement the care she received from her daughter who lived with her but who also cared for her own infant grandchild. However, despite coverage for varying types and levels of home and community-based services in all four states' Medicaid programs, two states had waiting lists that would at present preclude the availability of many of these services for elderly individuals seeking them.

Background

Individuals needing long-term care have varying degrees of difficulty in performing some activities of daily living without assistance, such as bathing, dressing, toileting, eating, and moving from one location to another. They may also have trouble with instrumental activities of daily living, which include such tasks as preparing food, housekeeping, and handling finances. They may have a mental impairment, such as Alzheimer's disease, that necessitates supervision to avoid harming themselves or others or need assistance with tasks such as taking medications. Although a physical or mental disability may occur at any age, the older an individual becomes, the more likely it is that a disabling condition will develop or worsen.

Assistance for such needs takes many forms and takes place in varied settings, including care in nursing homes or alternative community-based residential settings such as assisted living facilities. For individuals remaining in their homes, in-home care services or unpaid care from family members or other informal caregivers is most common. Approximately 64 percent of all elderly individuals with a disability relied exclusively on unpaid care from family or other informal caregivers; even among almost totally dependent elderly—those with difficulty performing five activities of daily living—about 41 percent relied entirely on unpaid care.[4]

Medicaid, the joint federal-state health-financing program for low-income individuals, continues to be the largest funding source for long-term care. In 2000, Medicaid paid 46 percent (about $63 billion) of the $137 billion

[4]Calculations based on Korbin Liu et al, *Changes in Home Care Use by Older People with Disabilities: 1982-1994* (Washington, D.C.: AARP, January 2000).

spent on long-term care from all public and private sources.[5] States share responsibility with the federal government for Medicaid, paying on average approximately 43 percent of total Medicaid costs. Within broad federal guidelines, states have considerable flexibility in determining who is eligible and what services to cover in their Medicaid program. Among long-term care services, states are required to cover nursing facilities and home health services for Medicaid beneficiaries. States also may choose to cover additional long-term care services that are not mandatory under federal standards, such as personal care services, private-duty nursing care, and rehabilitative services. For services that a state chooses to cover under its state Medicaid plan as approved by the Centers for Medicare & Medicaid Services (CMS), enrollment for those eligible cannot be limited but benefits may be. For example, states can limit the personal care service benefit through medical necessity requirements and utilization controls.

States may also cover Medicaid home and community-based services (HCBS) through waivers of certain statutory requirements under section 1915(c) of the Social Security Act, thereby receiving greater flexibility in the provision of long-term care services.[6] These waivers permit states to adopt a variety of strategies to control the cost and use of services. For example, states may obtain CMS approval to waive certain provisions of the Medicaid statute, such as the requirement that states make all services available to all eligible individuals statewide. With a waiver, states can target services to individuals on the basis of certain criteria such as disease, age, or geographic location. Further, states may limit the number of persons served to a specified target, requiring additional persons meeting eligibility and need criteria to be put on a waiting list. Limits may also be placed on the costs of services that will be covered by Medicaid. To obtain CMS approval for an HCBS waiver, states must demonstrate that the cost of the services to be provided under a waiver (plus other state Medicaid services) is no more than the cost of institutional care (plus any other Medicaid services provided to institutionalized individuals). These waivers permit states to cover a wide variety of nonmedical and social

[5]Based on our analysis of data from the Centers for Medicare & Medicaid Services, Office of the Actuary and The MEDSTAT Group. These figures include long-term care for all people, regardless of age. Amounts do not include expenditures for nursing home and home health care services provided by hospital-based entities, which are counted generally with other hospital services.

[6]42 U.S.C. §1396n(c) (2000).

services and supports that allow people to remain at home or in the community, including personal care, personal emergency response systems, homemakers' assistance, chore assistance, adult day care, and other services.

Medicare—the federal health financing program covering nearly 40 million Americans who are aged 65 or older, disabled, or have end-stage renal disease—primarily covers acute care, but it also pays for limited post-acute stays in skilled nursing facilities and home health care. Medicare spending accounted for 14 percent (about $19 billion) of total long-term care expenditures in 2000. A new home health prospective payment system was implemented in October 2000 that would allow a higher number of home health visits per user than under the previous interim payment system while also providing incentives to reward efficiency and control use of services. The number of home health visits declined from about 29 visits per episode immediately prior to the prospective payment system being implemented to 22 visits per episode during the first half of 2001.[7] Most of the decline was in home health aide visits.

Selected States Varied in Expenditures for and Design of Medicaid Home and Community Services

The four states we reviewed allocated different proportions of Medicaid long-term care expenditures for the elderly to federally required long-term care services, such as nursing facilities and home health, and to state optional home and community-based care, such as in-home personal support, adult day care, and care in alternate residential care settings. As the following examples illustrate, the states also differed in how they designed their home and community-based services, influencing the extent to which these services were available to elderly individuals with disabilities.

- New York spent $2,463 per person aged 65 or older in 1999 on Medicaid long-term care services for the elderly—much higher than the national average of $996.[8] While nursing home care represented 68 percent of New

[7]U.S. General Accounting Office, *Medicare Home Health Care: Payments to Home Health Agencies Are Considerably Higher Than Costs*, GAO-02-663 (Washington, D.C.: May 6, 2002).

[8]Medicaid expenditures for long-term care services for the elderly include nursing facilities, home health, personal support, and other care (which includes adult day care and alternate residential settings). We calculated a per capita cost based on the state or national population aged 65 or older and adjusted Medicaid expenditures for a state's health care costs in relation to the national average health care costs for 1997 to 1999 to at least partially account for geographic cost differences.

York's expenditures, New York also spent more than the national average on state optional long-term care services, such as personal support services. Because most home and community-based services in New York were covered as part of the state Medicaid plan, these services were largely available to all eligible Medicaid beneficiaries needing them without caps on the numbers of individuals served.

- Louisiana spent $1,012 per person aged 65 or older, slightly higher than the national average of $996. Nursing home care accounted for 93 percent of Louisiana's expenditures, higher than the national average of 81 percent. Most home and community-based services available in Louisiana for the elderly and disabled were offered under HCBS waivers, and the state capped the dollar amount available per day for services and limited the number of recipients. For example, Louisiana's waiver that covered in-personal care and other services had a $35 per day limit at the time of our work and served approximately 1,500 people in July 2002 with a waiting list of 5,000 people.[9]
- Kansas spent $935 per person aged 65 or older, slightly less than the national average. Most home and community-based services, including in-home care, adult day care, and respite services, were offered under HCBS waivers. As of June 2002, 6,300 Kansans were receiving these HCBS waiver services. However, the HCBS waiver services were not currently available to new recipients because Kansas initiated a waiting list for these services in April 2002, and 290 people were on the waiting list as of June 2002.
- Oregon spent $604 on Medicaid long-term care services per elderly individual and, in contrast to the other states, spent a lower proportion on nursing facilities and a larger portion on other long-term care services such as care in alternative residential settings. Oregon had HCBS waivers that cover in-home care, environmental modifications to homes, adult day care, and respite care. Oregon's waiver services did not have a waiting list and were available to elderly and disabled clients based on functional need, serving about 12,000 elderly and disabled individuals as of June 2002.

Appendix I summarizes the home and community-based services available in the four states through their state Medicaid plans or HCBS waivers and whether the state had a waiting list for HCBS waiver services.

[9]This HCBS waiver also covers environmental modifications to the home (such as wheelchair ramps) and personal emergency response systems. The dollar cap on service provided through this waiver increased as of September 1, 2002 to $55 per day.

Case Managers Predominately Offered Medicaid In-Home Care Services, but Number of Hours Varied

Most often, the 16 Medicaid case managers we contacted in Kansas, Louisiana, New York, and Oregon offered care plans for our hypothetical individuals that aimed at allowing them to remain in their homes. The number of hours of in-home care that the case managers offered and the types of residential care settings recommended depended in part on the availability of services and the amount of informal family care available. In a few situations, especially when the individual did not live with a family member who could provide additional support, case managers were concerned that the client would not be safe at home and recommended a nursing home or other residential care setting.

The first hypothetical person we presented to care managers was an 86-year-old woman, whom we called "Abby," with debilitating arthritis who is chair bound and whose husband recently died. In most care plans, the case managers offered Abby in-home care. However, the number of offered hours depended on the availability of unpaid informal care from her family and varied among case managers.[10]

- In the first scenario, Abby lives with her daughter who provides most of Abby's care but is overwhelmed by also caring for her own infant grandchild. Case managers offered from 4.5 to 40 hours per week of in-home assistance with activities that she could not do on her own because of her debilitating arthritis, such as bathing, dressing, eating, using the toilet, and transferring from her wheelchair. One case manager recommended adult foster care for Abby under this scenario.
- In the second scenario, Abby lives with her 82-year-old sister who provides most of Abby's care, but the sister has limited strength making her unable to provide all of Abby's care. Case managers offered Abby in-home care, ranging from 6 to 37 hours per week. One case manager also offered Abby 56 hours per week of adult day care.
- In the third scenario, Abby lives alone and her working daughter visits her once each morning to provide care for about 1 hour. The majority of case managers (12 of 16) offered from 12 to 49 hours per week of in-home care to Abby. The other four case managers recommended that she relocate to a nursing home or other residential care setting.

The second hypothetical person was "Brian," a 70-year-old man cognitively impaired with moderate Alzheimer's disease who had just been released

[10]Often, the case managers recommended additional services, such as nursing or other home health care, home-delivered meals, assistive devices for bathtubs such as grab bars or transfer seats, and/or personal emergency response systems.

from a skilled nursing facility after recovering from a broken hip. The case managers usually offered in-home care so that Brian could remain at home if he lived with his wife to provide supervisory care. If he lived alone, most recommended that he move to another residential setting that would provide him with needed supervision.

- In the first scenario, Brian lives with his wife who provides most of his care and she is in fair health. All 16 case managers offered in-home care, ranging from 11 to 35 hours per week. Two case managers also offered adult day care in addition to or instead of in-home care.
- In the second scenario, Brian lives with his wife who provides some of his care and she is in poor health. All but one of the case managers offered in-home care, ranging from 6 to 35 hours per week. One case manager recommended that Brian move to a residential care facility.
- In the third scenario, Brian lives alone because his wife has recently died. Concerned about his safety living at home alone or unable to provide a sufficient number of hours of in-home supervision, 13 of the case managers recommended that Brian move to a nursing home or alternate residential care setting. Two of the three care managers who had Brian remain at home offered around-the-clock in-home care—168 hours per week.

Table 1 summarizes the care plans developed for Abby and Brian by the 16 case managers we contacted.

Table 1: Number of Care Plans that Recommended that the Individual Remain at Home or Move to a Different Residential Setting

Amount of informal care available	Number of plans in which the individual remains at home	Range in hours per week of in-home care if individual remains at home	Number of plans in which the individual moves to a residential care setting
Abby (86-year old chair-bound woman with debilitating arthritis)			
Scenario 1: Abby lives with her daughter (who also cares for infant grandchild)	15	4.5 to 40[a]	1
Scenario 2: Abby lives with her sister (who has limited strength)	16	6 to 37[b]	0
Scenario 3: Abby lives alone (her daughter visits once a day)	12	12 to 49	4
Brian (70-year-old man with moderate Alzheimer's disease)			
Scenario 1: Brian lives with his wife (who is in fair health)	16	11 to 35	0
Scenario 2: Brian lives with his wife (who is in poor health)	15	6 to 35	1
Scenario 3: Brian lives alone	3	35 to 168	13

Note: Some care plans also offered additional services, such as nursing or other home health care, home-delivered meals, assistive devices such as a bathtub lift, and/or personal emergency response systems.

[a]In two care plans, case managers recommended that the daughter become licensed for a relative foster home and receive a payment that she could use to hire in-home or respite care for an unspecified number of hours. In addition, one care plan offered 8 hours per week of adult day care rather than in-home care.

[b]In one care plan, the case manager recommended that the sister become licensed for a relative foster home and receive a payment that she could use to hire in-home or respite care for an unspecified number of hours.

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

In some situations, two case managers in the same locality offered notably different care plans. For example, across the eight localities where we interviewed case managers, when Abby lived alone, four case managers offered in-home care while their local counterpart recommended a nursing home or alternative residential setting. The local case managers offering differing recommendations for in-home or residential care also occurred three times when Brian lived alone and once each when Abby lived with her daughter and when Brian lived with his wife who was in poor health. Also, in a few cases, both case managers in the same locality offered in-home care but significantly different numbers of hours. For example, one case manager offered 42 hours per week of in-home care for Abby when she lived alone while another case manager in the same locality offered 15 hours per week of in-home care for this scenario.

Case Managers in Some States Offered More In-Home Care, Alternative Residential Settings, or Other Supplemental Services

The home and community-based care that case managers offered to our hypothetical individuals sometimes differed due to state policies or practices that shaped the availability of their Medicaid-covered services. These included waiting lists for HCBS waiver services in Kansas and Louisiana, Louisiana's daily dollar cap on in-home care, and Kansas's state review policies for higher-cost care plans. Also, case managers in Oregon recommended alternative residential care settings other than nursing homes, and case managers in Louisiana and New York typically considered Medicare home health care when determining the number of hours of Medicaid in-home care to offer.

Neither of our hypothetical individuals would be able to immediately receive HCBS waiver services in Kansas and Louisiana due to a waiting list. As a result, they would often have fewer services offered to them—only those available through other state or federal programs such as those available under the Older Americans Act[11]—until Medicaid HCBS waiver services became available. Alternatively, they could enter a nursing home. The average length of time individuals wait for Medicaid waiver services was not known in either state. However, one case manager in Louisiana estimated that elderly persons for whom he had developed care plans had spent about a year on the waiting list before receiving services. In Kansas, as of July no one had yet come off the waiting list that was instituted in April 2002.

When case managers developed care plans based on HCBS-waiver services for our hypothetical individuals, the number of hours of in-home care offered by case managers could be as much as 168 hours per week in New York and Oregon but were at most 24.5 hours per week in Kansas and 37 hours per week in Louisiana. Case managers in Louisiana also tended to change the amount of in-home help offered little even as the hypothetical scenarios changed. This may have been because they were trying to offer as many hours as they could under the cost limit even in the scenario with the most family support available. (See table 2.)

[11]Funding from the Older Americans Act provides for supportive in-home and community-based services, including such services as nutrition, transportation, senior centers, health promotion, and homemaker services. 42 U.S.C. §§3001-3058ee (2000).

Table 2: Range in Amount of In-Home Care Offered to Individuals, by State

	In-home care offered (hours per week)			
Amount of informal care available	**Kansas**	**Louisiana**	**New York**	**Oregon**
Abby (86-year old chair-bound woman with debilitating arthritis)				
Scenario 1: Abby lives with her daughter (who also cares for infant grandchild)	5 to 22	28 to 37	4.5 to 40	7[a]
Scenario 2: Abby lives with her sister (who has limited strength)	6 to 14	24.5 to 37	15 to 35	9 to 16
Scenario 3: Abby lives alone (her daughter visits once per day)	12 to 24.5	24.5 to 35	42 to 49	15 to 42
Brian (70-year-old man with moderate Alzheimer's disease)				
Scenario 1: Brian lives with his wife (who is in fair health)	11 to 14.75	21 to 35	11 to 20	16 to 25
Scenario 2: Brian lives with his wife (who is in poor health)	14 to 21	21 to 28	6 to 35	22 to 29
Scenario 3: Brian lives alone	N/A[b]	N/A[b]	168[c]	35 to 168

[a]Only one case manager offered in-home care for this scenario. Two other Oregon case managers recommended that Abby stay at home, and the family caregiver become licensed for a relative foster home and receive a payment that she could use to hire in-home or respite care for an unspecified number of hours.

[b]All four case managers recommended care in a residential care setting such as a nursing home or assisted living facility.

[c]Only one case manager offered in-home care for this scenario. The other New York case managers recommended a residential care setting.

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Two states' caps or other practices may have limited the amount of Medicaid-covered in-home care that their case managers offered. For example, case managers in Louisiana tended to offer as many hours of care as they could offer under the state's $35 per day cost limit.[12] Therefore, as the amount of informal care changed in the different scenarios, the hours of in-home help offered in Louisiana did not change as much as they did in the other states. In Kansas, case managers often offered fewer hours of in-home care than were offered in other states, which may have been in part influenced by Kansas's supervisory review whereby more costly care plans were more extensively reviewed than lower cost care plans. A Kansas case manager also told us that offering fewer hours of care may reflect the case managers' sensitivity to the state's waiting list for HCBS services and an effort to serve more clients by keeping the cost per person low. In contrast, case managers in New York

[12]The cap was increased from $35 per day to $55 per day as of September 1, 2002. Also, the cap includes the cost of in-home care as well as a case management fee. According to a state official, Louisiana's daily cap for in-home HCBS waiver services reflects the state's budget constraints as well as the need to be cost-effective relative to nursing home care.

and Oregon did not have similar cost restrictions in offering in-home hours, with one case manager in each state offering as much as 24-hour-a-day care.

When recommending that our hypothetical individuals could better be cared for in a residential care setting, case managers offered alternatives to nursing homes to varying degrees across the states. Case managers in Louisiana recommended nursing home care in three of the four care plans in which care in another residence was recommended for Abby or Brian. In contrast, case managers in Oregon never recommended nursing home care for our hypothetical individuals. Instead, case managers in Oregon exclusively recommended either adult foster care or an assisted living facility in the five care plans recommending care in another residence. It was also noteworthy that two case managers in Oregon recommended that either Abby or Brian obtain care in other residential care settings in a scenario when she or he lived with a family member, expressing concern that continuing to provide care to Abby or Brian would be detrimental to the family. Case managers in Kansas, Louisiana, and New York only recommended out-of-home placement for Abby or Brian in scenarios when they lived alone.

State differences also were evident in how case managers used adult day care to supplement in-home or other care. For example, across all care plans the case managers developed for Abby and Brian (24 care plans in each state), adult day care was offered four times in New York and Oregon and three times in Kansas. However, none of the care plans developed by case managers in Louisiana included adult day care because it was in a separate HCBS waiver, and individuals could not receive services through two different waivers.[13]

Case managers in New York and Louisiana also often considered the effect that the availability of Medicare home health services could have on Medicaid-covered in-home care. For example, one New York case manager noted that she would maximize the use of Medicare home health before using Medicaid home health or other services. Several of the case managers in New York included the amount of Medicare home health care available in their care plans, and these services offset some of the Medicaid services that would otherwise be offered. In Louisiana, where

[13]The Louisiana adult day care waiver served approximately 525 people with a waiting list of 201 people as of July 2002.

case managers faced a dollar cap on the amount of Medicaid in-home care hours they could provide, two case managers told us that they would include the additional care available under Medicare's home health benefit in their care plans, thereby increasing the number of total hours of care that Abby or Brian would have by 2 hours per week. While six Kansas and Oregon case managers also mentioned that they would refer Abby or Brian to a physician or visiting nurse to be assessed potentially for Medicare home health, they did not specifically include the availability of Medicare home health in the number of hours of care provided by their care plans.

Concluding Observations

States have found that offering home and community-based services through their Medicaid programs can help low-income elderly individuals with disabilities remain in their homes or communities when they otherwise would be likely to go to a nursing home. States differed, however, in how they designed their Medicaid programs to offer home and community-based long-term care options for elderly individuals and the level of resources they devoted to these services. As a result, as demonstrated by the care plans developed by case managers for our hypothetical elderly individuals in four states, the same individual with certain identified disabilities and needs would often receive different types and intensity of home and community-based care for his or her long-term care needs across states and even within the same community. These differences often stemmed from case managers' attempts to leverage the availability of both publicly-financed long-term care services as well as the informal care and support provided to individuals by their own family members.

Mr. Chairman, this completes my prepared statement. I would be happy to respond to any questions you or other Members of the Committee may have at this time.

Contacts and Acknowledgments

For future contacts regarding this testimony, please call Kathryn G. Allen at (202) 512-7118 or John E. Dicken at (202) 512-7043. Other individuals who made key contributions include JoAnne R. Bailey, Romy Gelb, and Miryam Frieder.

Appendix I: Medicaid-Covered Home and Community-Based Services in Kansas, Louisiana, New York, and Oregon

Kansas, Louisiana, New York, and Oregon each offered home and community-based services through their state Medicaid plans or HCBS waivers. Kansas and Louisiana had waiting lists that generally made these services unavailable to new clients. Table 3 summarizes the home and community-based services available in the four states we reviewed and whether the states had a waiting list for HCBS waiver services.

Table 3: Medicaid Home and Community-Based Long-Term Care Services for Elderly in Four States

Home and community-based services (includes services offered in state plans and through waivers)	Kansas	Louisiana	New York	Oregon
In-home help with daily activities				
Personal care, providing hands-on assistance with activities of daily living such as eating, bathing, dressing, using the toilet, and grooming	○	○	●	●
Household support, providing assistance with instrumental activities of daily living, such as housekeeping and meal preparation	○	○	●	●
Home-delivered meals			●	●
Standby assistance during day or night	○	○		●
Adaptive items or changes to facilitate independence, mobility, or safety				
Environmental modifications, such as wheelchair ramp, or assistive devices or technology, such as bathtub lift or shower seat	○	○	●	●
Personal emergency response system	○	○	●	●
In-home medical care or counseling				
Periodic nursing evaluation	○	●	●	●
Home health services/medical equipment assistance	●	●	●	●
Nutritional counseling			●	
Case management	●	○	●	●
Help outside of home				
Adult day care	○	○	●	●
Help provided in community residential settings, such as assisted living facility, adult foster care, boarding home	○		●	●
Transportation		●[a]	●	●
Moving assistance			●	
Care for Caregiver				
Respite care in-home or out of home	○		●	●

● Available services

○ State had a waiting list for these services as of June 2002

Note: Services are only included in the table if the state Medicaid plan or HCBS waivers cover these services specifically for the elderly and/or disabled. In some cases, other services (such as respite care or transportation) may not be specifically included in the state plan or the waiver but could be provided indirectly through personal care attendants or other support services that are covered.

[a]In Louisiana, the HCBS waiver covers transportation to medical appointments only.

Source: GAO interviews with state Medicaid officials and review of state Web sites, 2002.

The CHAIRMAN. We have been joined. I recognize Senator Wyden is here. Do you have a comment or two before we proceed?

OPENING STATEMENT OF SENATOR RON WYDEN

Senator WYDEN. I will be very brief, Mr. Chairman. Thank you, first of all, for all of your leadership. The willingness that you have shown to constantly use this committee to aggressively inquire into these issues that are so important to older people is something that I very much appreciate. It is exactly what this committee ought to be doing. We appreciate your leadership.

I would just offer one short word with respect to the topic at hand, the question of home and community-based services for older people. We are so pleased with this report and its account for how Oregon is doing, back in the early 1970's when I was with the Gray Panthers, home and community based care struck us as one of the very best investments that you could possibly make, and that is true now given the demographic tsunami that is coming. I mean, we know in 2010, 2011, there are going to be millions of older people, and back then we tried to say, here is an opportunity to give older people more of what they want, which is to stay in the community, in home and community-based facilities, at a price that is less to the taxpayers than the institutional care.

So Oregon began then to pioneer with a special set of waivers, a variety of new approaches. We came to some of the same conclusions, I think, you have, Mr. Chairman, and that is this sort of one-size-fits-all approach does not make sense. I think this hearing gives us an opportunity to examine some important questions, particularly one that in our part of the world is very troubling to people, and that is that, somehow, when you do a good job in this country, when you are innovative, when you hold costs down, when you give good quality, somehow, the Federal Government then turns around and says, well, we are going to pay you less. We are going to give you reduced reimbursement for having done all this heavy lifting and being innovative and exploring new approaches.

So we are really pleased about the marks that GAO gave the Oregon program and I am especially grateful for your leadership, Mr. Chairman, and constantly using this committee to be on the cutting edge of gerontology.

The CHAIRMAN. Thank you very much, Senator, for your comments.

Now, from my area in Louisiana, I am very pleased that she was able to get up here. I do not know if you came up yesterday or when, but the weather is kind of wet down there and we are very glad that Shannon Broussard was able to make it up, although 20 inches of rain in New Orleans is just high humidity. [Laughter.]

In some States, it is about a 10-year total of rain. We got it in one day.

Ms. Broussard is Director of the Cajun Area Agency on Aging in Lafayette, LA, and will talk about their role in assisting older individuals in finding the best long-term care solution. Shannon, welcome to the committee and we are glad to have your input.

STATEMENT OF SHANNON BROUSSARD, EXECUTIVE DIRECTOR, CAJUN AREA AGENCY ON AGING, INC., LAFAYETTE, LA

Ms. BROUSSARD. Good morning, Chairman Breaux and distinguished members of the Senate Committee on Aging. I appreciate you asking me to come, and I really do want to apologize that Isidore followed us up here. It did shift a little east, so we were able to by way of Houston come in, so it was not too bad.

AAAs are the first place most older individuals will go to, or their family members, to find some long-term care services. We were established in 1973 through the Older Americans Act and we provide for a community-based structure of supportive and nutrition services. My AAA, Cajun Area Agency on Aging, serves eight primarily rural parishes in South Louisiana. Based on the unofficial 2000 census, there is approximately 91,000 people over the age of 60 in our eight-parish area.

Most served by the Act are the neediest, mostly women, many are rural, and most are poor, and thanks to the recent reauthorization of the Older Americans Act, we now have the National Family Caregiver Support Program, which enables us to meet the needs of some new constituents and they are the caregivers of older individuals, and so we are able to provide them some little bit of care, not as much as they would like, but it does help.

Thanks to the advances in health care and medical technology, life expectancy has increased to age 76.9, and with that increase in age, life expectancy, we have increased needs of long-term care services.

Currently, two options are available in Louisiana. You have institutional care or you have care provided by a family member. Though many older adults prefer receiving care in their home, Louisiana has an institutional bias. Medicaid is responsible for 80 percent of nursing facility care in Louisiana, and for the most part, government-subsidized care is the only available nursing care for patients. Currently, Louisiana Medicaid programs fund 1,804 in-home and community-based waiver slots. We have 518,000 people over the age of 65 and we have 1,800 waiver slots. What has happened with those waiver slots, we have to be at or below nursing home care, the cost of nursing home care.

Cajun Area Agency on Aging provides supportive and nutrition services to approximately 13,500 individuals. These programs have been the salvation for those who, if they would not have these services, would more than likely end up in nursing facilities.

Throughout Louisiana, family, friends, and neighbors have been the main source of help for the elderly members of our community. At present, the majority of the requests that Cajun Area Agency receives are for in-home care. That would be sitter services, respite services, or nursing care services, and many of the requests are from individuals who do not qualify for subsidized care and who need a little more than our home-delivered meals and homemaker services to stay at home.

As an agency, we do our best to refer services to those individuals so they can remain at home. All are advised to call the Medicaid request for services registry and have their name placed on the waiting list for waiver services, even though they are not financially eligible, because we figure that, in time, by privately paying

for home care, they will become Medicaid eligible, and hopefully, by the time they do that, they will be at the top of the list.

A comprehensive national policy that shifts the focus and funding of long-term care to community-based services is essential to meet the needs and address the desires of our older population. Independent dignity and choice are values we all possess, especially our older adults. By shifting national policies to home and community-based services, the quality of life for older adults will improve, taxpayers will be spared the cost of premature and expensive institutional care, and our nation's core values will be honored.

I do want to say that I do have some recommendations in my written testimony that I hope that you will have a chance to look through.

We get in between 10 and 15 calls a month from an older person or a family member looking for some type of care because we do not want to put Mom and Dad in a nursing home. We do our best. We will provide them a home-delivered meal. We will give them some caregiver services. We were able to serve some individuals a good amount of care for the first 6 months of our caregiver program, but now we have had to cut back because everything comes up to how much it costs. Those who did receive caregiver services were very pleased with it, so I think we need to continue and do our best to take care of people at home.

The CHAIRMAN. Thank you very much, Shannon. We will have some questions with you, and thank you for being up here under difficult circumstances.

[The prepared statement of Ms. Broussard follows:]

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STATEMENT OF SHANNON BROUSSARD
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LAFAYETTE, LOUISIANA

AND

MEMBER, NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

HEARING ON
"Long Term Care Services"
September 26, 2002 at 10 a.m.

Good morning Chairman Breaux and distinguished members of the Special Committee on Aging. My name is Shannon Broussard, and I am the Director of the Cajun Area Agency on Aging, Inc. in Lafayette, Louisiana. Thank you Chairman Breaux for inviting me to this important hearing on long-term care. My Board of Directors wants me to convey its appreciation for your interest in the long-term care needs of older adults. The Cajun Area Agency on Aging, Inc. is a member of the National Association of Area Agencies on Aging (n4a), the umbrella organization for the 655 area agencies on aging (AAAs) and more than 230 Title VI Native American aging programs in the U.S. and the following testimony includes information provided by n4a that reflects national trends concerning long term care services and AAAs.

The Mission of Area Agencies on Aging (AAA)

AAAs are most often the first place an older adult or their family member will turn when they need long term care services. Established in 1973 under the Older Americans Act (OAA), there are 655 AAAs across the country that provide a community-based structure for planning, service coordination, oversight and advocacy for supportive services for Americans aged 60 and over. The OAA also helps fund 232 Native American aging programs, known as "Title VI," to meet the unique needs of older American Indians, Aleuts, Eskimos and Hawaiians.

OAA services fall into five broad categories: information and access services; community-based services; in-home services; housing; and elder rights. These categories include support services such as congregate and home-delivered meals, home and personal care, caregiver support, transportation, senior centers, nursing

home ombudsman, employment and services for Native Americans and Native Hawaiians.

The Role of AAAs in Assisting Family Members and Older Adults in Identifying Long-term Care Resources

The wide range of OAA services administered by the aging network provides consumers with a broad range of service choices that best meet their individual needs. In particular, AAAs and Title VI agencies play a pivotal role in assessing their clients' needs and developing programs that respond to those needs. These agencies act as advocates for improved services for older persons and their families. They often serve as portals to care, assessing multiple service needs, determining eligibility, authorizing or purchasing services and monitoring the appropriateness and cost-effectiveness of services. AAAs provide direct services and contract with local providers to furnish other services in the community.

One of the greatest strengths of the Older Americans Act is the flexibility it allows AAAs and Title VI agencies to tailor services to the specific needs of older adults in their service area. While all AAAs and Title VI provide core support services as required by Title III of the Act, each adapts these services to appropriately, effectively, and efficiently serve their geographically, racially, culturally, and ethnically diverse local population.

The Cajun Area Agency on Aging, Inc.

My AAA, the Cajun Area Agency on Aging, Inc. serves eight, primarily rural, parishes (counties) in south Louisiana. There are more than 91,000 persons 60 years of age or older in our area. Because the Older Americans Act requires that we serve the *neediest elderly* first, and because there are so many older adults without family nearby to provide help of any kind, the older adults we now reach with in-home Older Americans Act services tend to be very frail and live alone; most are women, many are rural, and most are very poor. For those with family, the National Family Caregiver Support Program established in the recent reauthorization of the Older Americans Act, has allowed us to reach new constituents, the caregivers, who desperately need our assistance.

Thanks to advances in health care and medical technology, life expectancy has increased to an average of 76.9. However, with longer lives often comes the increased need for long-term care. Many older adults have only two options, institutional care or care provided by a family member. Though many older adults prefer receiving long-term care in their home, an institutional bias exists in Louisiana. Approximately 25,000 of Louisiana's impoverished older adults live in nursing facilities, where Medicaid subsidizes care. Medicaid is responsible for 80% of the nursing facility care in the state. For the most part, government-subsidized care is only available for nursing facility patients. Currently, Louisiana's Medicaid programs [Elderly & Disabled Adult & Adult Day Health Care Waivers] funds 1,804 in-home or community-based waiver slots for recipients [aged 65 or older] who would otherwise require institutional care.

Cajun Area Agency on Aging currently provides supportive and nutrition services to approximately 13,500 older adults, including home-delivered meals, light housekeeping, assisted transportation, and social opportunities for those who can attend community centers. These programs have been the salvation for many individuals who, in their absence, would have had to be placed in nursing facilities. These services, however, are non-medical in nature and many older adults also need in-home health services such as monitoring of medical devices and medication management. A high percentage of older adults who need this kind of assistance do not require twenty-four hour nursing care and can remain viable members of their communities, if they receive appropriate in-home assistance that meets basic health care needs.

As previously stated, most individuals who need long-term care services would much prefer or are desperate to remain in their own homes or in home-like settings, such as assisted living. For the past several decades, however, the bulk of public dollars for long-term care have supported services in nursing facilities. Additionally, the average family cannot afford the cost of assisted living facilities without some financial assistance.

Many consumers still assume that long-term care is covered under Medicare. The concept of purchasing long-term care insurance is relatively new and not really accepted or understood in Louisiana. The cost of such policies is also a barrier. Dual coverage policies that cover both institutional care and home care are now also available. However, these policies are very expensive and not a viable solution for low and even many middle-income individuals.

Consumer Questions

Louisiana

Throughout the state of Louisiana, family, friends and neighbors continue to be the main source of help for elderly community members, providing transportation and shopping assistance, social support and a wide variety of other services that successfully maintain older adults in the community. Even so, many older adults lack such support and depend on formal social services to meet critical needs.

At present, the majority of requests Cajun Area Agency on Aging receives for assistance have been for in-home care, such as sitter services, respite care and nursing care. Many calls are from individuals who do not qualify for government-subsidized care, and who need more critical services than typical social services currently provide. We do our best to refer older adults to services that will enable them to remain at home. All are advised to call the *Medicaid Request for Services Registry* and have their loved one's name placed on the waiver program waiting list, whether they are financially eligible [income limits – up to three times SSI amount - $1,635] or not. Most individuals who are privately paying for home care will soon become eligible for Medicaid, due to the high costs of that care.

National - Eldercare Locator

One service that the Cajun AAA, Inc. and all AAAs use to connect older adults with needed long-term care services is the Eldercare Locator. Established in 1991 by the U. S. Administration on Aging, the Eldercare Locator is as a public service

administered by n4a and the National Association of State Units on Aging. The Eldercare Locator, a nationwide toll-free 800 number, provides individuals who call with access to more than 4,800 state and local information and referral (I&R) service providers, identified for every ZIP code in the country. The database also includes special purpose I&R telephone numbers for Alzheimer's hotlines, adult day care and respite services, nursing home ombudsman assistance, consumer fraud, in-home care complaints, legal services, elder abuse/protective services, information on Medicare/Medicaid/Medigap, tax assistance and transportation. In November 2001, the Eldercare Locator website was launched and currently receives approximately 25,000 hits a month.

Since its inception, the Eldercare Locator has fielded over 822,100 calls from individuals and their family members seeking answers to questions on long-term care services. In the period between October 2001 and August 2002, the Locator received over 111,500 calls. The most common information sought during this period include information on home care services (18,851 requests), financial assistance (10,358 requests), transportation (8,215 requests), and housing information (6,968 requests). During this period there have also been spikes in calls on prescription drugs (April & May) and caregiving (June).

Recommendations for Improvement to the Current System

The overwhelmingly preferred choice of older adults, as well as individuals with disabilities who need long term care services is for home and community-based care. Home and community-based care allows individuals to maintain their independence

and age with dignity in the comfort of their own homes, in familiar neighborhoods and communities.

Our federal policies do not adequately recognize that the most cost-effective form of long-term care is provided through home and community-based services. Older Americans Act programs and the services provided by AAAs are a major component of an array of federal, state, local, and private support services paid for through public and private financing. Moreover, despite the substantial role that family caregivers play in providing long-term care, the United States lacks a coherent set of policies to assist informal caregivers. Demographic changes, the aging of the 77 million baby-boomers, and increasing longevity will intensify current delivery and financing difficulties.

A comprehensive national policy that shifts the focus and funding of long-term care to community-based services is essential to meet the needs and address the desires of America's aging population. Independence, dignity and choice are strongly held values by all Americans, and individuals with physical or cognitive limitations and impairments are no exception. By shifting national policies toward home and community-based services, the quality of life of older adults will improve, taxpayers will be spared the cost of premature and expensive institutional care, and our nation's core values will be honored.

A sound home and community-based system of long-term care provides a coordinated and broad range of service that addresses the medical, social and

environmental needs of the individual. n4a has issued a series of policy papers on the nine components critical to a comprehensive home and community-based system of care, which include: Medicaid waivers for home and community-based services, Older Americans Act services, caregiver support, housing options, transportation services, nutrition and wellness programs, mental health services, adult protective services and a dependable paraprofessional workforce. The individual papers are provided as an Addendum to this testimony. Key recommendations from each follow:

- Increase the federal Medicaid match to states by 3% and dedicate the resulting savings in long-term care funds to home and community-based services;
- Reduce categorical funding barriers and support efforts to partner Medicaid waivers with other local, state, and federally assisted programs such as Older Americans Act services, federal housing programs, and community mental health services that provide home and community-based care;
- Promote greater coordination between the Medicare and Medicaid programs to address the interaction of acute and chronic care needs as a means of avoiding unnecessary hospitalization;
- Encourage approval of waiver proposals that integrate care for persons eligible for both Medicaid and Medicare;
- Increase funding for all OAA programs and services by a minimum of 10% above the FY 2002 levels;
- Double the initial $125 million appropriation for the NFCSP to ensure that the much-needed benefits this vital program provides reach thousands more caregivers and their families;
- Maintain and enhance the flexibility of the OAA to enable AAAs and Title VI agencies to most appropriately and effectively respond to the specific needs of diverse populations of older adults in their communities;

- Offer a range of financial and other incentives, including tax credits/deductions and cash vouchers to all family caregivers, and affordable health insurance and guaranteed retirement security for individuals who leave the workforce to provide care to a family member;

- Increase financial assistance for home and community-based services on the federal and state levels to support aging in place for the majority of older adults who want to stay in their homes;

- Develop new residential models of housing that meet universal design standards, including new housing that is accessible, adaptable and affordable for the increasingly diverse older adult population;

- Enhance, coordinate and adequately fund the vast array of federal and state financed transportation services to provide viable and affordable options for the growing population of older adults who need services;

- Support increased funding for the Federal Transit Agency's *Section 5310* program, which funds transportation programs for older adults and persons with disabilities in the reauthorization of the Transportation Equity Act for the 21st Century (TEA-21) in 2003;

- Expand and revitalize community senior nutrition programs to better meet the specialized nutrition needs of an increasingly ethnically diverse population and individuals with multiple health conditions;

- Enhance resources to meet the increasing demand for home-delivered meals resulting from the growth of the 85 and older population which is expected to double by 2030;

- Increase collaboration among mental health services providers and streamline federal, state and privately financed mental health services to coordinate and strengthen existing service and delivery systems;

- Promote prevention and early intervention measures that increase collaboration among acute and long-term care providers;

- Provide adequate funding at the federal, state and local level to develop and enhance elder abuse prevention services;

- Continue to research the causes of abuse and neglect while acknowledging that many forms of domestic mistreatment are crimes and should be treated as such;

- Establish basic training in nursing skills and require the successful completion of a competency test for all paraprofessional personnel; and

- Encourage employers to provide higher wages and improved benefits for all paraprofessional staff through incentive programs.

ADDENDUM

Advocacy. Action. Answers on Aging.

Home and Community-Based Services

Introduction

As individuals age, and chronic conditions increase, the need for long-term care services grows. Long-term care refers to a broad range of services, paid and unpaid and provided in a variety of settings, for persons who need assistance with daily activities due to a physical or mental limitation. The availability of formal or informal support and services, an individual's needs and preferences and the ability to finance needed services all play a part in determining the setting in which an individual will receive long-term care services. According to a recent General Accounting Office (GAO) report, of the almost six million adults age 65 and over with long-term care needs, only 20 percent receive care services in a nursing home or other institutional setting, with the remaining 80 percent receiving assistance at home and in the community. Home and community-based care, which allows individuals to maintain their independence and age with dignity in the comfort of their own homes, in familiar neighborhoods and communities, is overwhelmingly the preferred choice of older adults, as well as individuals with disabilities.

Our federal policies do not adequately recognize that the most cost-effective form of long-term care is provided through home and community-based services. These services are currently provided through a fragmented and inconsistent array of federal, state, local, and private support services paid for through public and private financing. Moreover, despite the substantial role that family caregivers play in providing long-term care, the United States lacks a coherent set of policies to assist informal caregivers. Demographic changes, the aging of the 77 million baby-boomers, and increasing longevity will intensify current delivery and financing difficulties.

The 1999 Supreme Court *Olmstead v. L.C.* decision has accelerated the shift of national policy toward home and community-based services. In *Olsmtead,* the Court ruled that the unnecessary segregation of individuals in long-term care facilities constitutes discrimination under the Americans with Disabilities Act (ADA). States are required, when it is appropriate and reasonable to do so, to serve individuals with disabilities in community settings rather than in institutions. The Court directed each state to develop a comprehensive, effective working plan to place qualified individuals in less restrictive settings and to assure that people come off waiting lists at a reasonable pace.

Olmstead affects those at risk of institutionalization as well as those currently institutionalized. Therefore, any reform efforts brought on by the decision must involve changes not only to the long-term provision of public health services (primarily Medicaid) but also to housing, transportation and other fundamental support services that are essential to fully integrate individuals with disabilities into least restrictive settings.

Executive Summary

A comprehensive national policy that shifts the focus and funding of long-term care to community-based services is essential to meet the needs and address the desires of America's aging population. Independence, dignity and choice are strongly held values by all Americans, and individuals with physical or cognitive limitations and impairments are no exception. By shifting national policies toward home and community-based services, the quality of life of older adults will improve, taxpayers will be spared the cost of premature and expensive institutional care, and our nation's core values will be honored.

A sound home and community-based system of long-term care provides a coordinated and broad range of services that address the medical, social and environmental needs of the individual. n4a believes the following principles must be adhered to for a home and community-based system to best meet the needs of those it serves, including the not-too-distant future needs of the baby boomer generation.

Reform Medicaid

Medicaid, the largest public program financing long-term care, has an inherent bias toward institutionalization. Congress established the home and community-based service waiver in 1981 to attempt to reduce this bias. The Medicaid waiver program gives states the option to apply for waivers to fund home and community-based services for people who meet Medicaid eligibility requirements for nursing home care. A recent study by the Assistant Secretary for Planning and Evaluation with the U.S. Department of Health and Human Services found that average spending on the aged and disabled under the Medicaid home and community-based waiver saved money – providing for an individual under the waiver program costs $5,820 a year compared to $29,112 for nursing home care. Even so, nursing home care remains a basic service under Medicaid, while states still face a burdensome waiver process to offer home and community-based services.

Build Upon the Successes of the Older Americans Act

The Older Americans Act (OAA) has been the foundation of services for older adults throughout the country since its enactment in 1965 and forms the nucleus of a national system of home and community-based services. OAA funds, and the services they make possible, are augmented by leveraging state and local government funding, as well as private sector, foundation, participant and volunteer contributions. OAA funding has not kept pace with inflation or the growing population of individuals eligible for services. Significant increases in federal appropriations are crucial to assure the availability of services and programs that enhance the ability of older Americans to live with maximum independence.

Enhance Support for Family Caregivers

The majority of people of all ages with chronic disabling conditions rely on family members or friends as their primary source of care. Nearly one out of every four households (23 percent or 22.4 million households) is involved in caregiving to persons age 50 or older. Among older adults with long-term care needs, nearly 95 percent receive some or all of their care from informal caregivers who often suffer emotional, physical and financial hardships as a result of caregiving. Furthermore, cultural and demographic changes are reducing the pool of available caregivers just as the baby boomer generation approaches retirement age. The National Family Caregiver Support Program, enacted in 2000 as part of the Older Americans Act reauthorization, and numerous state programs provide support services for caregivers, but current federal funding is insufficient to meet caregiver needs.

Link Affordable Housing with Needed Support Services

Housing security is critical to the health and well being of older adults. The home and community-based system will not succeed without the provision of affordable and accessible housing for older adults. Greater coordination needs to occur between housing and service providers to guarantee that support services, such as meals, personal assistance and housekeeping, as well as health services, are readily available and easily obtainable. While policy initiatives are underway to increase existing assisted living facilities stock, convert existing public housing into accessible housing, and provide increased coordination of support and housing services, progress has been slow and more commitment to these efforts by policymakers is needed.

Develop Systems to Help Older Adults Retain Mobility

Mobility is essential for an individual to live at home and in the community. Transportation provides necessary access to medical care, shopping for daily essentials and the ability to participate in cultural, recreational and religious activities. Feelings of isolation and loss have been reported among older adults who can no longer use personal automobiles. Public policy must focus on the provision of safe, reliable and convenient alternative means of transportation for those for whom driving is no longer an option, as well as on efforts to help older adults retain their licenses and cars for as long as possible.

Design Responsive Mental Health Services

Good mental health is fundamental to the well being of older adults and has a major impact on quality of life and optimal functioning. Yet, as the U.S. Surgeon General's 1999 report on mental health points out, too many older adults struggle with mental disorders that compromise their ability to participate fully in life. Older adults underutilize mental health services, for both social and systemic reasons, and care professionals and social services personnel frequently fail to recognize the signs and symptoms of mental illness. Service gaps, lack of collaboration among service agencies, and shortages of trained personnel also contribute to a poorly functioning mental health service system. Policymakers must work toward resolving current challenges in the design and delivery of mental health services that affect quality of life for the older population.

Expand Nutrition and Wellness Programs

Good nutrition and daily physical activity both play important roles in preventing or forestalling the onset of chronic conditions as well as reducing the effects of existing conditions. Nutrition programs such as congregate and home-delivered meals, provided through the Older Americans Act and other government programs, not only improve participants' dietary intake but also provide a social outlet for older adults at risk of isolation. Unfortunately, long waiting lists for these meals programs exist throughout the country. And while fewer structured programs exist to promote physical activity, the social, economic and health benefits of daily exercise must be recognized. Greater emphasis needs to be placed on the development and expansion of programs that promote sound nutrition and increased physical activity at the federal, state and local level.

Increase Efforts to Prevent Elder Abuse and Neglect

The dependence on others for care and assistance whether at home or in a facility leaves older adults, especially the most frail, vulnerable to abuse, neglect and exploitation. Adult protective services are designed to reduce the incidence of abuse and neglect and are essential to making it possible for older adults to remain safely in their homes and communities. Many older adult victims do not report abuse and many cases are not prosecuted. Staffing shortages, poor training and heavy caseloads contribute to unsatisfactory protective services. Greater outreach and educational efforts and increased collaboration among service providers at the federal, state and local level are important measures that can be taken to prevent and decrease all types of elder abuse.

Collaborate on Solutions to Workforce Shortages

At a time when an increasing percentage of the population needs direct care services, our nation is facing a serious shortage of workers in this industry. Paraprofessional personnel shortages can be attributed to, among other things, low pay, inadequate employee benefits including lack of health insurance, insufficient training and minimal chance for career advancement. Moreover, health care agencies have a hard time maintaining employees due primarily to poor reimbursement rates from both public (Medicare, Medicaid) and private providers. Furthermore, the care that is provided by these workers is undervalued by society. Policymakers need to work collaboratively with workers unions, service providers and consumers to recruit and retain a stable, reliable workforce.

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Home and Community-Based Services for Older Adults: Medicaid Waivers

The Medicaid program is the major source of financing for long-term care, providing services for low-income individuals or those that become low-income as a result of paying for long-term care or medical needs. While Medicaid long-term care expenditures are still predominantly institutional, with nearly 70 percent of long-term care expenditures going to nursing homes and other institutional settings, there has been a growing trend toward home and community-based services that started with the implementation of the Medicaid Waiver program in 1981. The use of Medicaid waivers as an effective means of reducing long-term costs was highlighted in a recent study by the Assistant Secretary for Planning and Evaluation with the U.S. Department of Health and Human Services, which found that the annual cost for providing care for an individual under the waiver program is $5,820 compared to $29,112 for nursing home care.

Issue Background

Medicaid waivers are often an essential element in the establishment of comprehensive and coordinated service delivery systems for older adults that offer a broad range of choice of home and community-based long-term care services along with institutional care. Furthermore, the need to comply with the *Olmstead v. L.C.* Supreme Court decision to avoid inappropriate institutional care provides an additional impetus for expansion of Medicaid waivers to foster development of a wide range of home and community-based care options.

Sections 1915 (program waivers) and 1115 (research and demonstration waivers) of the Social Security Act allow states to apply to the federal government to obtain exemptions from certain Medicaid statutes. The 1915 (c) waiver is most relevant to home and community-based services because it allows services to be provided to certain recipients at home or in other community-based settings rather than in institutional or long-term care facilities. The categories of eligible populations include the elderly, disabled, mentally ill and people with specific illnesses or conditions.

The waiver typically allows states to overcome statewide and comparability requirements. Also, the 1915 (c) waiver often includes a request not to apply the same income eligibility requirements throughout the state. The 1915 (c) waivers allow states to provide services beyond the scope of traditional Medicaid benefits to cover additional medical and non-medical services, including home health, case management, personal care, homemaker, adult day health, rehabilitation, and respite care. In addition, other services such as in-home support, transportation, and environmental modifications may be included if the state demonstrates they are necessary in order to avoid institutionalization.

The purpose of the 1115 waiver is "to experiment, pilot or demonstrate projects which are likely to assist in promoting the objectives of Medicaid." 1115 waivers can be used to waive a much broader set of Medicaid requirements than 1915 (c) waivers as long as program changes do not create additional federal costs or are budget neutral. These waivers typically permit states to expand eligibility or benefit packages by generating savings and reinvesting the savings into program expansion.

Proposed 1115 waiver programs must include a research component that provides new information on models that adapt Medicaid to specific state needs. Also, the proposed benefit package must not be less than the full coverage currently offered in the state.

Waiver Process

Medicaid waivers must demonstrate cost-effectiveness or budget neutrality. Proposed changes under a waiver request cannot cost the federal government more than the expected Medicaid costs for the traditional Medicaid program under the same time period. The Office of Management and Budget must determine that 1915 waivers are cost-effective and that 1115 waiver requests are budget neutral.

The evaluation of the cost effectiveness and budget neutrality of Medicaid waiver proposals should take into consideration potential cost savings not only for Medicaid but also for Medicare, Supplemental Security Insurance, and Social Security Disability Insurance. The current lack of coordination between Medicare and Medicaid exacerbates the fragmentation of acute and long-term care.

Policy Recommendations

Medicaid waivers will continue to play a critical role in the ability of states to develop comprehensive and coordinated service delivery systems for older adults that offer a broad range of home and community-based long-term care services. While Medicaid spending for home and community-based services is increasing, policymakers must work to make requirements less restrictive and Medicaid dollars more available to the states as the demand for home and community-based care continues to grow.

n4a urges policymakers to:

- **Increase the federal Medicaid match to states by 3% and dedicate the resulting savings in long-term care funds to home and community-based services;**
- **Reduce barriers for states and federally recognized Indian tribes to implement additional 1915 (c) waivers so they may offer increasing alternatives to institutional care for individuals with long-term care needs;**
- **Reduce categorical funding barriers and support efforts to partner Medicaid waivers with other local, state, and federally assisted programs such as Older Americans Act services, federal housing programs, and community mental health services that provide home and community-based care;**
- **Promote greater coordination between the Medicare and Medicaid programs to address the interaction of acute and chronic care needs as a means of avoiding unnecessary hospitalization;**
- **Encourage approval of waiver proposals that integrate care for persons eligible for both Medicaid and Medicare; and**
- **Make financial incentives available from Medicare for Medicaid home and community-based long-term care providers who provide services that help reduce Medicare costs for dually- eligible consumers.**

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Home and Community-Based Services for Older Adults: Older Americans Act

The Older Americans Act (OAA) has been the foundation of services for older adults in the United States since its inception in 1965 and forms the nucleus of our national system of home and community-based services for older Americans. The OAA provides funding to states for a range of community planning and service programs to older Americans at risk of losing their independence. Since its enactment, the OAA has been amended fourteen times to expand the scope of services, increase local control and responsibility, and add more protections for the frail elderly.

Issue Background

The Aging Network

To develop and implement the wide array of OAA services, a system of federal, state and local agencies, known as the aging network was established. The core of the aging network is the U.S. Administration on Aging (AoA), State Units on Aging (SUA), and Area Agencies on Aging (AAA). The AoA and SUAs were established under the initial Act; AAAs were added in 1973 to respond to the needs of Americans aged 60 and over in every local community. The network also includes Native American aging programs, known as "Title VI agencies," service providers, and aging research, education, and advocacy organizations. Together these groups work to maintain the comprehensive and coordinated system of services that make up the national home and community-based care system for the aging. Currently, there are 56 SUAs, 655 AAAs, 236 Title VI agencies, and over 29,000 direct service providers throughout the United States.

OAA Programs and Services

The OAA services available through the aging network fall into five broad categories: information and access services; community-based services; in-home services; housing; and elder rights. These categories include support services such as congregate and home-delivered meals, in-home services, caregiver support, transportation, senior centers, nursing home ombudsman, employment and services for Native Americans and Native Hawaiians.

The wide range of OAA services administered by the aging network enable it to direct consumers to service choices that best meet their individual needs. In particular, AAAs and Title VI agencies play a pivotal role in assessing community needs and developing programs that respond to those needs. These agencies act as advocates for improved services for older persons and their families. They often serve as portals to care, assessing multiple service needs, determining eligibility, authorizing or purchasing services and monitoring the appropriateness and cost-effectiveness of services. They also provide direct services as well as contract with local providers to furnish services in the community.

All AAAs and Title VI agencies support a range of home and community-based services, but services vary across communities. While there is much consistency in the types of essential home and community-based services available across the country, these services are customized to reflect local needs and caregiver resources.

Congress took an important first step toward recognizing the value and considering the needs of caregivers with the enactment of the National Family Caregiver Support Program (NFCSP), as part of the OAA amendments of 2000. The NFCSP provides grants to States to help hundreds of communities assist thousands of family members who are struggling to care for their older loved ones who are ill or who have disabilities.

Policy Issues

OAA appropriations provide funds to the AoA for administrative and program expenses for all titles of the OAA with the exception of Title V: the Community Service Employment Program, which falls under the jurisdiction of the Department of Labor. While the OAA has received incremental funding increases over the last several years, it has not kept pace with inflation or the growing population of individuals eligible for services. As a result there are unmet needs throughout the country. AAAs and Title VI agencies have skillfully managed care for vulnerable aging populations by maximizing private and public resources to ensure that essential services are available to millions of minority, frail and low-income older persons in need of comprehensive long-term care. However, as the aging population continues to grow — with more people living longer but facing chronic illness and frailty — the aging network will increasingly be unable to meet the demands for care without significant funding increases. This year, the President's budget request for FY 2003 includes $1.34 billion in funding to AoA for OAA programs, an overall decrease of $8 million from last year.

Policy Recommendations

The necessity for increased OAA funding will only continue to grow with the coming retirement of 77 million baby boomers and the demand for long-term care expected to more than double by 2030. Significant increases in federal appropriations are crucial to assure the availability of OAA programs and services and enhance the ability of older Americans to live with maximum independence.

n4a urges policymakers to:

- **Increase funding for all OAA programs and services by a minimum of 10% above the FY 2002 levels;**
- **Double the initial $125 million appropriation for the NFCSP to ensure that the much-needed benefits this vital program provides reach thousands more caregivers and their families;**
- **Ensure that the OAA is reauthorized on time when the current authorization expires in 2005, allowing for a seamless transition and avoiding a lapse in authorized funding which will be more important than ever as the elderly population and demand for services continue to skyrocket;**
- **Maintain and enhance the flexibility of the OAA to enable AAAs and Title VI agencies to most appropriately and effectively respond to the specific needs of diverse populations of older adults in their communities;**
- **Provide staff and technology resources within the aging network to track older adults and their caregivers together as they move through the home and community-based care system; and**
- **Encourage the AoA to begin planning for the 2005 White House Conference on Aging immediately and ensure that national aging advocacy groups have ample opportunity to provide input on the agenda and conference objectives.**

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Home and Community-Based Services for Older Adults: Informal Caregiving

Family care of older adults is an important and valued role in our society, and one that is important to family preservation and well being. Most older adults with long-term care needs live at home, either in their own homes, with or without a spouse, or in the home of a close relative or friend. In this setting the major long-term provider is the family and, to a lesser extent, other unpaid "informal" caregivers. The overwhelming majority of non-institutionalized older adults with disabilities — about 95 percent — receive at least some assistance from relatives, friends and neighbors. Almost 67 percent rely solely on unpaid help, primarily from wives or daughters.

Issue Background

Long-term care of older adults by family members is central to the functioning of current social and health care systems and is therefore a critical policy issue. Informal caregiving has always been the dominant source of care to most individuals in need. Nearly one out of every four households (23 percent or 22.4 million households) is involved in caregiving to persons age 50 or older. In fact, caregivers now provide nearly $200 billion in unpaid care. Without this essential component of care, the long-term care system and the Medicare and Medicaid programs would not be able to meet the needs of our older population. With the current system facing growing demands for support services, it is essential to provide family caregivers with the resources they need to provide this valuable care.

Research on family caregiving has not only consistently validated its significant role in long-term care, but has also illuminated the problems and needs experienced by informal caregivers which have been of increasing concern to both aging advocates and policymakers. The caregiver role frequently results in enormous emotional, physical, and financial hardships, even though it is willingly undertaken and often is a source of great personal satisfaction. Caregivers commonly experience a sense of burden, fair-to-poor physical health and high rates of depression. Among caregivers who provide unpaid care for a family member or friend age 50 or older, some 15 percent report that they have experienced a physical or mental health problem due to their caregiving duties. Worries over paying for care especially plague middle income families, who are not eligible for public benefits, yet cannot afford the out-of-pocket costs of care.

Half or more of family caregivers juggle work, family and caregiving responsibilities, resulting in work disruptions and lost productivity. The cost in lost wages and benefits to family caregivers has been estimated to be $109 per day, according to a report by the American Council of Life Insurers in March 2000. While the Metlife Mature Market Group in June 1997 estimated the cost of informal caregiving in terms of lost productivity to U.S. businesses to be $11.4 billion annually.

Need for Overall Policy

Despite vast research on family caregivers, widespread awareness of the volume of family care, and general agreement that family care is necessary to balance the costs of long-term care, a comprehensive policy on family care of frail older adults has not emerged. A patchwork of family support programs of various kinds does, however, exist. These include community-based programs designed to help family members who are giving care, such as educational programs, support groups, and respite services. They also include long-term care services, usually for low-income people, that provide benefits directly to the older person and thus relieve family members to some extent.

In addition, many states support the family financially through tax incentives or direct payment. Taken together, these activities represent meaningful efforts to support family caregivers. In the last three to four years,

significant progress has been made at the national level with the advent of such policy initiatives as The Family and Medical Leave Act and The National Family Caregiver Support Program (NFCSP) under the Older Americans Act Amendments of 2000. In particular, the NFCSP enables local communities to connect families with information on caregiver resources and local services, provides counseling, training and peer support for caregivers, and provides services needed by older adults and their families, such as respite care, in-home services and adult day care.

Policy Recommendations

As the home and community continue to be promoted as the preferred setting for the delivery of long-term care services to older adults and persons with disabilities, national policy must recognize and support the significant role that family members and other informal caregivers play in the provision of that care. The coming retirement of the baby boom generation and increased demand for long-term care will only intensify demands on family caregivers. A national policy on long-term care should provide services available in the recipient's preferred surroundings, be characterized by privacy, choice, and control over daily decisions, and maintain any self-selected mutually agreed upon relationships between caregiver and care recipient.

n4a urges policymakers to:

- **Double the initial $125 million appropriation for the NFCSP to ensure that the much-needed benefits this vital program provides could reach thousands more caregivers and their families;**
- **Offer a range of financial and other incentives, including tax credits/deductions and cash vouchers to all family caregivers, and affordable health insurance and guaranteed retirement security for individuals who leave the workforce to provide care to a family member;**
- **Promote consumer direction in long-term care;**
- **Assure that family caregivers of adults with physical, as well as cognitive, impairments have a place to turn to for support; and**
- **Encourage the use of the Internet and other information technology to improve access to and information about caregiver support services and community resources.**

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Home and Community-Based Services for Older Adults: Housing

As home and community-based care continues to evolve as the preferred choice of older Americans for long-term care services, the important role that housing plays in the matrix of care must be recognized. A wide range of housing problems confront older adults and policymakers must identify and implement interventions to address them.

Issue Background

Housing provides a context for living that involves health, security and safety, privacy, neighborhood and social relationships, status, community facilities and services. Housing is the basis for independent functioning and is at the core of home and community-based services for older adults. The residential setting can either facilitate or inhibit an older adult's ability to age safely, independently, and with the dignity. Appropriate housing helps older adults remain longer in the preferred setting of the community and delays moves to more expensive institutional health care settings. The comfort and ease that comes with living in a familiar environment can help older adults cope with changes in physical and mental capacities that often accompany aging.

Despite being essential to well being, appropriate housing is unattainable for many older Americans. Current federal estimates suggest that the need for safe, affordable, accessible and suitable housing for older adults is not currently being met and will only increase as the nation's older population continues to grow. Older adults who are most likely to have housing problems include the frail, disabled, and rural older adults and those with low incomes. Millions of older adults live in housing that is in poor condition, is costly, or fails to accommodate physical disabilities. Some do not have access to the supportive services that can make the difference between continuing to live independently and being forced to live in an institution. Housing problems are endemic to both older adult homeowners and renters. Housing issues for both groups include affordability, availability, suitability and overall housing quality.

Policy Issues

Older adults spend a disproportionately large portion of their incomes for shelter. Because older adults generally live on fixed incomes, they face the hardships of finding affordable rents, or maintaining a house and coping with rising costs, including mortgage payments, property taxes, repairs, and utilities. The insufficient supply of affordable housing and excessive costs are especially threatening to older adults with incomes at or below the poverty level. Despite efforts to increase the supply of publicly subsidized housing, only a small portion of the housing needs of older adults are currently met.

As the older population lives longer, there is a greater likelihood of disability resulting from chronic illness. For frail older adults, the integration of supportive services with suitable physical housing can forestall or prevent the need for institutionalization or more extensive home care. Both subsidized and private housing developments are finding growing numbers of older adult residents "aging in place" and experiencing greater difficulty with activities of daily living as a result of increased limitations. Services are needed to maintain quality of life and support continued residence in housing. In the absence of critical supportive services, including meals, housekeeping, and social services directed by qualified service coordinators, individuals are at greater risk of relocation, typically to more restrictive living situations, such as nursing homes. Service-rich housing has been found to reduce both the number of hospital and nursing home admissions and the number of days spent in such facilities.

Policy Recommendations

Given the critical importance of housing to the success of home and community-based care for older adults, the provision of suitable living facilities for older Americans needs to be a major public policy goal. The focus must be on providing housing that both meets the needs of independent older adults and addresses the supportive service needs of frail older adults. The future challenge is to develop new models of supportive housing and provide a range of residential settings and portable services to increase the choices for frail older adults.

n4a urges policymakers to:

- **Increase financial assistance for home and community-based services on the federal and state levels to support aging in place for the majority of older adults who want to stay in their homes;**
- **Develop new residential models of housing that meet universal design standards, including new housing that is accessible, adaptable and affordable for the increasingly diverse older adult population;**
- **Support the conversion of public housing for older adults into supportive housing and increase the number of service coordinators provided in housing facilities; and**
- **Encourage more helpful household arrangements through incentives for making home modifications that help older adults remain independent in their homes.**

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Home and Community-Based Services for Older Adults: Transportation

Transportation is the vital link between home and community. It connects individuals of all ages to the places where they can fulfill their most basic needs –- the grocery store for food, the worksite for employment, friends' homes and recreational sites for social interaction, and houses of worship for spiritual sustenance. But, these resources in the community are only beneficial to the extent that transportation can make them accessible to those who need them.

Issue Background

The core values of Americans, autonomy and independence, are reflected in the fact that most prefer and rely on the convenience of their own automobile to access the outside world. However, as individuals age, they eventually lose the physical or financial ability to maintain a car. When they stop driving, older adults can experience a drastic decline in mobility.

In suburban and rural areas, home to nearly 80 percent of the older adult population, destinations are often too far to walk, public transit is poor or unavailable, taxis are costly, and special services are limited. In particular, distance from public transportation presents a major barrier as less than half of households in urban and suburban areas are within a half-mile of a transportation stop or station. In rural areas, the situation is more difficult, with only one in eight households being within a half-mile of public transportation.

Transportation problems are closely correlated with poor income, self-care problems, isolation and loneliness. Reduced mobility puts an older person at higher risk of poor health, as the ability to obtain the goods and services necessary for good health and welfare is reduced. In addition, independence is stifled and loss of self-sufficiency can fuel depression.

Policy Issues

Older adults who drive their own car experience few transportation problems. However, the picture is vastly different for non-drivers. Those who stop driving usually rely on family and friends, but asking for and accepting rides can be difficult, particularly for those raised in a tradition of self-sufficiency. As a result, non-drivers take fewer and shorter trips, and rides are taken around the schedules and convenience of others. Older non-drivers take only two trips per week compared with six trips per week of older drivers.

For some older adults who have relied on an automobile, learning to use public transportation, if available in their community, can be very difficult. Routes may be geared to commuters and not to the places where seniors frequent. Walking to and from pick-up points can be tiring and dangerous as roads and walkways are not always pedestrian-friendly. It has been reported that more than one-fifth of individuals age 50 and older see the lack of sidewalks and resting places as a major barrier to walking.

Access to public transit, both fixed-route and paratransit systems, needs to be enhanced for older adults with cognitive disabilities. Some older adults with cognitive disabilities may need the additional assistance of "through the door" services to reach their destinations safely. Sensitivity awareness training also should be provided for drivers in how to interact with passengers with dementia and other special needs.

The number of older adults will continue to grow. While many of these older Americans will be healthy and mobile, many others, particularly the "old-old," will need to utilize alternative modes of transportation. Since the passage of the Americans with Disabilities Act (ADA) in 1990, availability of paratransit

services to older adults has been declining as operators adhere more tightly to ADA criteria in the face of financial constraints. As a result, transportation options for some older adults have declined.

Policy Recommendations

Mobility is essential for an individual to live at home and in the community, yet policymakers have focused little attention on how to help older adults retain their mobility. Efforts are needed to help older adults keep their licenses and cars as long as possible, as well as to provide safe, reliable and convenient alternative means of transportation for those for whom driving is no longer an option.

n4a urges policymakers to:

- **Enhance, coordinate and adequately fund the vast array of federal and state financed transportation services to provide viable and affordable options for the growing population of older adults who need services;**
- **Support increased funding for the Federal Transit Agency's *Section 5310* program, which funds transportation programs for older adults and persons with disabilities in the reauthorization of the Transportation Equity Act for the 21st Century (TEA-21) in 2003;**
- **Examine and expand existing public transit systems to improve accessibility and availability to older adults especially in suburban and rural communities where fixed route services are less accessible;**
- **Promote the provision of non-emergency medical transportation as an allowable expense under Medicare;**
- **Provide training to ensure public transit drivers are sensitive to the special needs of older adults;**
- **Encourage greater coordination and communication between community transportation providers and social service providers; and**
- **Promote a pedestrian and transit user friendly environment and develop standards to be incorporated into local building and zoning regulations.**

Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Mental Health

Mental health is fundamental to the well being of older adults, and has a major impact on quality of life. Yet, the 1999 report by the U.S. Surgeon General on mental health points out that too many older adults struggle with mental disorders that compromise their ability to participate fully in life. The cost of this loss of vitality to older adults, their families, their caregivers, and the country is staggering. Despite substantial numbers of older persons with mental health difficulties, the role of mental health in the continuum of care is largely neglected. There is considerable evidence that many of the problems of older Americans caused by poor mental health could be avoided if treatment and prevention resources were enhanced. Because chronic mental disorders are over-represented in long-term care populations, planning and providing for essential services presents an important health and long-term care policy challenge.

Issue Background

Mental Health and Aging

Most older adults enjoy good mental health, but nearly 20% of those who are 55 years and older experience mental disorders that are not part of normal aging. The most common disorders, in order of prevalence, are anxiety disorders such as phobias and obsessive-compulsive disorder; severe cognitive impairment, including Alzheimer's disease; and mood disorders, such as depression. Schizophrenia and personality disorders are less common. Mental disorders can range from problematic to disabling to fatal. The rate of suicide is higher among older adults than any other age group. Older adults with mental illness vary widely with respect to the onset of their disorders. Some have suffered from serious and persistent mental illness most of their adult lives, while others have had periodic episodes of mental illness. A substantial number of older adults experience mental health disorders or problems for the first time late in life -- problems frequently exacerbated by bereavement or other losses which tend to occur in old age.

Minority populations are expected to represent 25% of the older adult population by 2030, up from 16% in 1998. With the expected jump in this population, there is a need for mental health interventions that are effective for ethnic minority older adults. At present, members of ethnic minority groups are less inclined than whites to seek treatment, despite higher rates of poverty and greater health problems. In addition, there is an insufficient number of mental health professionals from ethnic minority groups, which leads to language barriers and inadequate services in mental health programs.

Delivery of Services to Older Adults in Community Settings

Older Americans under utilize mental health services. A number of individual and systemic barriers impede the provision of adequate mental health care to older persons. These include the stigma surrounding mental illness and mental health treatment; lack of outreach to older adults; denial; access barriers; fragmented and inadequate funding for mental health services; lack of collaboration and coordination among primary care, mental health, and aging services providers; gaps in services; and shortages in professional and paraprofessional staff trained in the provision of geriatric mental health services. While mental health services for older adults are provided in diverse settings, far greater emphasis should be placed on community-based care, provided in homes and in outpatient settings, and through community organizations.

Initiatives in Mental Health and Aging

A number of notable initiatives have been undertaken to address issues surrounding mental health services. Among these are

efforts to: encourage collaboration in the delivery of mental health and supportive services; organize consumer advocacy groups; increase public education of mental health issues; support research specific to older adults with mental health needs; and expand and better educate the geriatric mental health workforce. These efforts provide an excellent foundation for confronting critical challenges in mental health and aging.

Policy Recommendations

A national crisis in geriatric mental health care is emerging and policymakers, practitioners, and researchers are facing many challenges in meeting the needs of a diverse and growing aging population. Careful consideration must be given to confronting these challenges, especially in light of the expected increase of older adults in our population and their need for a wide range of mental heath services. The crisis will require partnerships across service systems and disciplines to address the mental health needs of older adults.

n4a urges policymakers to:

- **Increase collaboration among mental health services providers and streamline federal, state and privately financed mental health services to coordinate and strengthen existing service and delivery systems;**
- **Promote prevention and early intervention measures that increase collaboration among acute and long-term care providers;**
- **Aggressively recruit and train geriatric mental health professional and paraprofessional personnel needed in the fields of medicine, mental health, and social services;**
- **Increase public awareness and education campaigns to reduce the stigma surrounding mental illness and the resulting underutilization of mental health services;**
- **Increase mental health and aging research to improve understanding of the biological, behavioral, social, and cultural factors related to mental illness, especially for at-risk and underserved populations;**
- **Encourage greater consumer advocacy and involvement in issues of access, range, and quality of mental health services that depend in large part on consumer and family involvement, participation, and advocacy; and**
- **Ensure that mental health professionals acquire adequate knowledge of the cultural background and values of the ethnic minorities they serve, which will enable them to determine the service approaches that best meet their mental health needs.**

Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Nutrition and Wellness

An essential component of an effective home and community-based system of services for older adults is the promotion of healthy aging through nutrition and physical activity programs. Current research shows that it is never too late to begin to make good eating and exercise choices for healthy aging. Good nutrition is essential to maintaining cognitive and physical functioning and plays an essential role in the prevention or management of many chronic diseases such as heart disease, cancer, stroke, diabetes, and osteoporosis. Research has also indicated that the substantial protective effect of physical activity persists even to advanced old age. In fact, some community-based wellness programs, which may feature exercise classes, chronic condition self-management classes, and personal health action plans, have resulted in a significant reduction of hospital use by older adults.

Issue Background

Nutrition

Adequate nutrition is critical to healthy functioning and quality of life. Current nutrition programs and education have been the cornerstone of the Older Americans Act and aging network programs, improving the nutritional intake of older adults and decreasing social isolation. Available to seniors age 60 and older, these programs are targeted to those with the greatest social and economic need. But, while 3.2 million older Americans participate in senior meal programs each year, an estimated 4 million more older Americans suffer from food insecurity or the inability to afford, prepare or gain access to food.

The provision of nutrition services is especially important to ethnic minority older adults, who tend to have a higher incidence of chronic disease. Culturally appropriate meal programs are the entry point for improved nutrition and community engagement. For immigrant or refugee groups who may have limited English language skills, senior nutrition programs help address cultural isolation, augment diet choices limited by fixed incomes, and bring needed services in a culturally supportive setting.

One program that has been of particular benefit to older adults who lack adequate nutrition is the Seniors Farmers Market Nutrition Pilot Program. The program awards grants to States, U.S. Territories and Indian tribal governments to provide coupons to low-income seniors for use at farmers markets, roadside stands, and community-supported agriculture programs. According to the U.S. Department of Agriculture, in 2001, fresh, nutritious, locally grown fruits, vegetables and herbs were available to 3,700 seniors at 929 farmers markets as well as 542 roadside stands and nearly 90 community supported agriculture programs through this important program.

Physical Activity

While social service providers offer some fitness programs for older adults, these programs need to be recognized as an essential partner to healthy aging and significantly expanded. Fitness programs offer older adults instruction on how to exercise safely and effectively, as well as information regarding access to convenient fitness programs. Researchers have found that exercise by older adults even in their mid-nineties can greatly increase overall muscle strength as well as bone density. Exercise can also improve an older adult's balance and ability to walk, resulting in maximum independence and a decreased incidence of falls.

Wellness/Health Promotion

Health promotion programs designed to meet the special needs of older adults can lead to improved behaviors and health status. Current health promotion and disease

prevention activities funded under the Older Americans Act include health risk assessments and screenings, nutrition screening and educational services, physical fitness, and health promotion programs on chronic disabling conditions.

The Medicare program has also made great strides in recognizing the importance of health promotion in healthy aging by covering preventive services, such as mammography, pap tests and other cancer screenings, bone mass measurements, diabetes monitoring and self-management, influenza immunizations, and pneumococcal vaccinations. In addition, the Centers for Medicare and Medicaid Services (CMS) is taking steps to actively promote Medicare clinical preventive services that contribute to a healthy aging experience. Under the Healthy Aging Project, CMS, in collaboration with other federal health agencies, is exploring Medicare's role in reducing behavioral risk factors, which account for 70% of the physical decline that occurs during aging. This project has focused on identifying interventions that increase Medicare-funded preventive services and promote behavioral change such as smoking cessation, proper diet and exercise among older adults.

Policy Recommendations

Good nutrition and daily activities that lead to overall wellness are integral components of an effective home and community-based service system for older adults as they play important roles in preventing or forestalling the onset of chronic conditions as well as reducing the effects of existing conditions. The benefits of, and need to expand, programs that promote sound nutrition and increased physical activity must be addressed at the federal, state and local level.

n4a urges policymakers to:

- **Expand and revitalize community senior nutrition programs to better meet the specialized nutrition needs of an increasingly ethnically diverse population and individuals with multiple health conditions;**
- **Enhance resources to meet the increasing demand for home-delivered meals resulting from the growth of the 85 and older population which is expected to double by 2030;**
- **Support efforts to expand on the Seniors Farmers Market Nutrition Pilot Program by building on collaborative efforts between local service providers and farmers to improve access by older adults to healthy and nutritious foods;**
- **Promote and integrate support for physical activity throughout the aging network so that all older adults and aging network providers are aware of the health benefits of even moderate physical activity; and**
- **Advocate that public health funding be available for senior wellness programs, as well as Medicare preventive health coverage, to promote healthy aging and reduce future disease-related costs.**

Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Adult Protective Services

Adult protective services provide an important safeguard for frail older adults. Individuals who are severely disabled and unable to meet their basic personal needs are generally dependent on family members, friends, and paid caregivers for care and support. Their physical or mental impairments and resultant dependency make them extraordinarily vulnerable to mistreatment and neglect. These situations have high potential for abuse, neglect and exploitation, and measures to protect the rights and interests of the frail and impaired in domestic settings are essential.

Issue Background

Elder Abuse among the Older Adult Population

In its common usage, the term "elder abuse" represents all types of mistreatment or abusive behavior toward older adults. This mistreatment can be an act of commission (abuse) or omission (neglect), intentional or unintentional, and of one or more types: psychological, physical, or financial. While elder abuse occurs in domestic and institutional settings alike, it is more prevalent in domestic settings, where the majority of disabled older adults live. Older adults living at home are also isolated and largely invisible to the rest of the community, which puts them at greater risk for mistreatment and neglect.

Researchers have offered various theoretical explanations of why elder abuse occurs: an overburdened caregiver, a dependent elder or perpetrator, a mentally or emotionally disturbed perpetrator, and a childhood of abuse and neglect. Others theorize that structural forces such as the imbalance of power within relationships or the marginalization of older adults within society have created conditions that lead to conflict and violence.

It is difficult to estimate the prevalence of domestic mistreatment of older adults or its level of severity. Community surveys conducted in the last decade show that 4 to 6 percent of older adults report experiencing incidents of domestic elder abuse, neglect and exploitation. According to the National Elder Abuse Incidence Study (NEAIS), mandated by Congress in 1996, the number of reported cases of domestic abuse nationwide increased steadily from 117,000 in 1986 to 296,000 in 1996. The study estimated that 449,924 persons ages 60 and older living in domestic settings were abused, neglected, or exploited. While for each new incident of elder abuse, neglect, or self-neglect reported four or five incidents went unreported.

Little is known about the consequences of elder abuse because of the difficulty in disentangling the effects of the aging process, disease, and abuse. Researchers have found that abused older adults include higher proportions of people with depression or other mental distress, a history of physical abuse, and financial difficulties than are found among their non-abused cohorts. Clinicians suggest that other effects of elder abuse include feelings of learned helplessness, alienation, guilt, shame, fear, anxiety, denial, and posttraumatic stress syndrome. These findings underscore the need for more research, not only on the psychological and physical consequences of mistreatment, but also on the effectiveness of current intervention strategies.

Elder Abuse and Public Responses

Law enforcement, medical, nursing, health care, social work or other professionals in the community are the first line of defense for victims of neglect or abuse. All 50 states and the District of Columbia have enacted legislation to provide adult protective services for victims of abuse. These mandates usually provide for intervention, advocacy, and mandatory reporting of suspected abuse or neglect to a specific agency, some at the state level, but most often at the county or city level. These laws generally require various licensed

professionals to report incidents of abuse and neglect. After a report is received, a designated agency is obligated to investigate within a set time frame and if the mistreatment is verified, the investigation may involve the police, courts, social services or other community agencies. When the form of mistreatment is passive neglect, those affected can receive services, such as financial assistance, physical and mental health assessments, home maintenance, home health care, meal preparation, counseling and other interventions.

Many states use Social Services Block Grant (SSBG) funds for the protection of adults and children. Federal support for protective services is also provided through the Older Americans Act, which funds legal, guardianship, ombudsman, as well as more traditional nutrition and supportive services such as transportation, meals and personal care.

Policy Issues

With the growth of awareness of the problem of abuse and neglect of older adults has come an increased concern over the inadequacies in our adult protective services systems. Shortcomings in both policy and services seriously compromise the ability of the frail elderly to live in the community. Multiple factors most likely contribute to the ineffectiveness of protective services, including the victim's reluctance to accept help and the inadequacy of services offered. In addition, protective service agencies cannot refuse cases, and are routinely placed in the unenviable position of receiving those cases that other voluntary agencies find too difficult to handle. Burdened by heavy caseloads, insufficient staffing and inadequate training for staff, protective services in some locales have become stigmatized by other agencies and by the public.

Policy Recommendations

For protective services to succeed in the context of long-term care, several changes are required. The most important of these involve networking across service systems, amending state laws, and improving resources for adult protective services.

n4a urges policymakers to:

- **Provide adequate funding at the federal, state and local level to develop and enhance elder abuse prevention services;**
- **Continue to research the causes of abuse and neglect while acknowledging that many forms of domestic mistreatment are crimes and should be treated as such;**
- **Increase community awareness and understanding of elder abuse through a nationwide public education campaign;**
- **Encourage training and education to combat elder abuse for a wide range of professionals, particularly those working in adult protective services and law enforcement;**
- **Establish neighborhood watch programs and similar initiatives designed to provide assistance and referrals; and**
- **Promote recruitment, continued training, and support for the network of volunteers serving in the adult protective services system.**

Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Workforce Shortage

The services provided by home health care agencies and nursing home facility workers are a critical component of the health care and long-term care industries. While the need for these paraprofessional workers — home health aides, nursing home aides, unlicensed assistance personnel, certified nursing assistants, personal aides, personal assistants, and home health assistants — is increasing, current recruitment and retention efforts are not sufficient to overcome shortages and secure minimum needed personnel. Employers continue to face high turnover rates and lack of available staff. This coincides with a demand for personal care and home health aides that is projected to grow by 58 percent between 1998 and 2008, according to the U.S. Department of Labor, Bureau of Labor Statistics.

Issue Background

There are several significant factors that contribute to the scarcity of paraprofessional personnel who provide direct care to the frail and elderly in their homes or nursing facilities. The high turnover and shortage of paraprofessional personnel results from such factors as low pay and status, poor benefits, high emotional demands, few options for training, high proportion of young and part-time workers, and limited potential for advancement.

Paraprofessional personnel often have burdensome workloads and too many patients to be able to provide adequate care. Chronic under funding by Medicaid and Medicare and a regulatory system that focuses on fines and penalties, often for failing to provide adequate personnel, also contribute significantly to the workforce shortage. The pool of younger workers for entry-level positions continues to diminish while at the same time seniors are living longer and their numbers are increasing.

The nursing home and home health industries are not providing sufficient and appropriate wages, benefits and training for paraprofessional personnel positions. In 1998, according to the Bureau of Labor Statistics, home health and personal care aides made a median wage of $7.58 an hour, while nursing home aides made a median wage of $7.99 an hour. A year later, the median wage of home health care aides was $9.77 an hour, and the bottom 25 percent of home health aides earned just $8.12 an hour, according to the National Association of Home Care/Hospital and Healthcare Compensation Service's *Homecare Salary & Benefits Report* 2000-2001.

Making the picture even worse is the fact that home health aides normally do not receive pay for their travel time between jobs. And, while nursing home aides may receive benefits, home health aides usually do not. Moreover, although some employers give slight pay increases with experience and added responsibility, training options and advancement opportunities are undefined and inadequate.

Consequences of Shortages

Of all staff caring for patients, paraprofessional personnel have the most contact with clients and provide most of their care. They are responsible for bathing, feeding, hydrating, and ensuring that patients do not acquire bedsores and other conditions stemming from poor mobility. In some cases, paraprofessional personnel are the only or main source of human contact. In this demanding environment, staff shortages can contribute to quality of care issues and circumstances in which workers may become prone to neglectful and abusive behavior.

Policy Issues

A number of states are now tackling the shortage of paraprofessional personnel in various ways. Some states are experimenting with new programs to establish increased wages and benefits, such as health insurance and payment for transportation costs, and improved training designed to recruit new workers to the ranks of paraprofessional personnel. For example, as of November 2000, 16 states have implemented "wage pass-through" legislation that requires that some portion of Medicaid payment increases to long-term care providers be used to increase wages and benefits for nursing aides.

Policy Recommendations

While state efforts to develop a more qualified, stable frontline workforce are encouraging, decisive federal action must be taken to effectively address the national workforce shortage which will likely worsen over time as demand continues to increase.

n4a urges policymakers to:

- **Establish basic training in nursing skills and require the successful completion of a competency test for all paraprofessional personnel;**
- **Encourage employers to provide higher wages and improved benefits for all paraprofessional staff through incentive programs;**
- **Support research and demonstration programs to find solutions to the paraprofessional workforce shortage, and assess the feasibility of applying successful state efforts at the national level;**
- **Train paraprofessional personnel in ethnic sensitivity, addressing language barrier issues, and ethical care and compassion;**
- **Introduce comprehensive guidelines to encourage home health care agencies and nursing homes and their paraprofessional staff to meet and exceed minimum quality assurance standards; and**
- **Promote recognized safety guidelines for paid caregivers and their clients.**

The CHAIRMAN. Lisa Yagoda is the Senior Staff Associate for Aging at the National Association of Social Workers here in Washington. I think you are going to talk about barriers to long-term care and the role of caseworkers in helping them find those services, so we are glad to have you here.

STATEMENT OF LISA YAGODA, MSW, LICSW, SENIOR STAFF ASSOCIATE FOR AGING, NATIONAL ASSOCIATION OF SOCIAL WORKERS, WASHINGTON, DC

Ms. YAGODA. Thank you. Good morning. On behalf of NASW's nearly 150,000 members, I thank Chairman Breaux, Senator Stabenow, Senator Wyden, and their fellow Senators on the committee for holding this hearing. NASW appreciates the opportunity to highlight some of the issues professional social workers are faced with when educating clients about long-term care services that are available in the community.

The combination of physiological, psychological, and social changes that accompany aging can have a significant impact on the quality of life for seniors, often necessitating a need for supportive services and the skills of a professional social worker.

Social workers are prepared for professional practice through a combination of education and field experience. Professional social workers are licensed or certified and adhere to a strict code of ethics. In our work with older Americans, professional social workers practice in a wide variety of settings and at a variety of levels. Social workers provide services to active and healthy older people living in the community, as well as those who reside in institutions.

In the long-term care arena, social work services are provided not only to the older adults, but also to family members and caregivers. The ultimate goal of social work services for older individuals is to reinforce their existing strengths and capacities while maximizing independence and well being.

When informing and educating the public about long-term care services, we as policymakers and service providers are faced with the formidable task of how to best meet the needs of all care recipients while at the same time providing a streamlined system of access, outreach, and service delivery. This is a particularly difficult task for social workers who are on the front lines mainly because current entitlement programs are not designed to customize services and meet the wide range of presenting problems that we typically encounter when working with older adults.

When we consider how best to inform consumers about the array of long-term care options available in the community, we must first acknowledge some inherent challenges, which include determining who the client is, what the most appropriate services are, who is eligible for services, who can access services, and what are the barriers to care.

You may be surprised to learn that a major challenge is defining the client or consumer. Sometimes an older person seeks services directly, but oftentimes it is not the older adult but a family member, trusted friend, clergy member, neighbor, or other service provider who is seeking services on the senior's behalf. When this happens, competing or conflicting needs may exist, such as the concern for safety versus the desire for independence.

There are many reasons as to why these barriers to service may exist. For example, a care recipient may not consent to receiving the services or does not recognize there is a problem in the first place. This may be due to a mental illness, dementia, or perhaps just a fear of loss of control. In situations where the care recipient does agree to receiving services, the services that are most appropriate to meet their needs might be cost prohibitive or simply just might not exist.

The way care recipients perceive services is also a contributing factor in that means-tested services often are viewed negatively by older adults and their families and accepting these services may be seen as a personal failure.

Another challenge is a lack of a central, uniform point of entry into home and community-based services. Older adults or family members may not know there is a problem, but they just do not know where to begin their quest for seeking services.

When designing policies and programs to educate, support, and serve seniors, it is important to consider the goals of the program. Aging is a process. As such, education about aging needs to be interspersed throughout the entire lifespan. As an aging society, we need to be more aware of what lies ahead of all of us and what resources are available.

Outreach and education should take place at all the various points of entry. Information also should be available in places in the community where older Americans and their caregiver would most likely gain access. Support and information must be available in different venues, accessible to both seniors and their caregivers.

Though a wide array of services do exist in the community to maintain and improve the quality of life for older Americans, it is important for this committee and for all of us to continue to seek strategies for improvement. NASW appreciates the opportunity to come before you this morning and we look forward to continuing to work with this committee as it pursues its mission.

The CHAIRMAN. Ms. Yagoda, thank you so very much for being with us.

[The prepared statement of Ms. Yagoda follows:]

ational Association of Social Workers

Testimony of Lisa Yagoda, MSW, LICSW
Senior Staff Associate for Aging
National Association of Social Workers

Faces of Aging: Personal Struggles to Confront the Long-Term Care Crisis

Before the United States Senate Special Committee on Aging

September 26, 2002

Good morning. I am Lisa Yagoda, a licensed clinical social worker and the Senior Staff Associate for Aging at the National Association of Social Workers (NASW). On behalf of our nearly 150,000 members nationwide, I thank Chairman Breaux, Ranking Member Craig, and their fellow Senators serving on the Special Committee on Aging for convening this hearing on a critical piece of the long-term care matrix. NASW appreciates the opportunity to highlight some of the issues professional social workers encounter when helping older adults and their families to navigate the complex web of long-term care services that are available in the community.

As you are well aware, aging is a major catalyst in the changing landscape of our society. With the aging of the baby boomer cohort and the continued lengthening of the average life span, the number and proportion of older Americans is quickly rising. The U.S. Administration on Aging (AoA) has predicted that by 2030, our country will have roughly 70 million people over the age of 65--more than double the amount in 2000. Older Americans comprised 12.4% of the entire U.S. population in 2000, but are expected to increase substantially to 20% in 2030. Within that time frame, the number of those 85 and over is expected to double, while the number of those 100 and older is expected to triple. Given that the changing demographics of our older population will continue through the coming years, our nation will face many challenges in meeting the needs of older Americans.

As Americans age, they face a combination of physiological, psychological, and social changes. Although most older people enjoy relatively good health, more than a third, 34.7%, experience limiting chronic medical conditions according to AoA in its *2001 Profile of Older Americans*. AoA also noted in the same publication that more than half of the older population, 54.5%, experience at least one disability, either physical or nonphysical, with more than a third (37.7%) having at least one severe disability. Likewise, more than 14% have some difficulty in carrying out activities of daily living, and more than 21% experience difficulties with instrumental activities of daily living. These combinations of factors have momentous, permanent effects on the quality of life for older Americans, often necessitating a need for supportive services and thereby the skills of a professional social worker.

Social work is a distinct profession with rigorous, specialized education and training requirements, state licensure, certification, and ethical standards. Depending on the requirements of the particular practice setting, social workers may hold a bachelor's, master's, or doctorate

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degree in social work. Social workers use a biopsychosocial approach, which examines the person, group, or community in the context of their environment and facilitates appropriate problem solving in that framework. Professional social workers are knowledgeable not only about human development and behavior, but also about social, economic, and cultural issues and how these areas interact and affect our daily lives.

Social work is unique among the health and mental health professions in that it considers the physical, mental, and social aspects of individuals-- an approach that is vital to the appropriate provision of services to older adults and their families. In working with older Americans, social work professionals practice in a wide variety of settings, including: Area Agencies on Aging, mental health facilities, family service agencies, ombudsman programs, educational institutions, veterans services programs, skilled nursing facilities, nursing homes, rehabilitation centers, hospices, adult day care facilities, assisted living facilities, nutrition programs, adult protective services, elder abuse programs, hospitals, and in private practice. Social workers provide services to active and healthy older people living in their communities as well as to those who reside in institutions.

Social workers are a vital link between older adults and the services designed to help them. Professional social workers provide services at many levels: direct service, supervision, management, policy development, research, planning, education, and training. In direct practice, professional social workers address a broad spectrum of issues in multiple roles and render a variety of services, such as assessment, case management, mental health, medical-social services, referral, service coordination, advocacy, community building, monitoring of care, mediation, investigation, intervention, and counseling. These social work services are provided not only to the older adult, but also to his or her family members or other caregivers in conjunction with other providers so the older adult's independence and well-being are maximized. The ultimate goal of social work services for older individuals is to reinforce their strengths and capacity.

NASW offers an Aging Section for our membership, which provides in-depth information on aging social work practice, policy, research, and advocacy. NASW is also involved in strategic partnerships with other research, policy, practice, and advocacy organizations regarding aging issues. Currently, NASW is serving as an outreach partner with the Public Broadcasting Service (PBS) for an upcoming documentary series on caregiving for older and disabled Americans. "And Thou Shalt Honor: Caring for Our Aging Parents, Spouses and Friends" will air on October 9, 2002 on PBS stations.

It is important to note that the expected increase of older Americans will create a greater demand for both aging services and professionals with knowledge and expertise in aging. The Center for Health Workforce Studies, applying U.S. Bureau of Labor Statistics (BLS) data, projected that the need for health care workers will increase from 10.9 million workers in 2000 to more than 14 million in 2010. The projected rate of growth in health care occupations during that period is 28.8 percent, more than twice the rate for non-health-related occupations. A similar trend holds true for social workers in health care. In 2000, BLS reported that of roughly 601,000 self-identified social workers, 187,000 were employed in health care. The projected need in 2010 is estimated to be 252,000—an increase of 65,000, or 35 percent.

Furthermore, education has an effect on supply. Finding comprehensive, useful, and affordable postgraduate training in geriatrics is a challenge. Even when professional social workers have received training in gerontology, continuing education is needed to hone skills and to translate classroom learning into actual practice. However, little funding is available for gerontological continuing education for professional social work practitioners. Incentives such as scholarships, stipends, and loan forgiveness are also needed to attract social workers to the field.

It is imperative to recognize the diverse strengths and needs of older people when developing program and services for this population. The formidable task will be how we develop policies that best meet the needs of all older Americans, while at the same time providing a streamlined system of access, outreach, and service delivery.

Our society has rightly shouldered the responsibility of providing a wide range of services for older Americans, including those provided through Medicare, Medicaid, Social Security, and the Older Americans Act. However, several challenges exist in assessing the wide array of needs, in informing consumers and their families about available services, and guiding them to access points for services. These challenges include confusion about who is the client, what the services are and who can access them, the negative perception of services, and barriers to care and services. Note that each older person and his or her circumstances are distinct; an inflexible, cookie-cutter approach will not meet an older individual's needs in an optimal fashion.

You may be surprised to learn that a major challenge is defining the client or consumer. Sometimes an older person seeks services directly. Oftentimes, a family member, trusted friend, neighbor, clergy member, service provider, or even a stranger will seek services for a senior. Also competing or conflicting needs may exist, such as concern for safety versus desire for independence. For example, an older adult who is competent may prefer to remain living in his or her own home, but family members may feel that the older person would be better served in a more structured living environment. Furthermore, means-tested services often are viewed negatively by older adults and their families; using these services may be seen as a personal failure. This process is particularly difficult for individuals who have always been self-reliant and never sought public services.

Other barriers to services may occur as well. Sometimes, the family does not recognize there is a problem. If strained family relationships exist, it may be too painful to acknowledge a problem with a loved one. Many families are geographically dispersed and unable to help provide hands on support. Also, in order to access many community-based services, the client must consent to receiving service. For several reasons, some clients may be unwilling or unable to provide consent. There are many reasons as to why this happens. The client might not recognize there is a problem because of mental illness, dementia, fear of loss of control, or an overarching need to be independent.

Given the wide continuum of needs experienced by older Americans, there is no central point of entry into home and community-based services. Clients might be referred by an acute care hospital, skilled nursing facility, or rehabilitation hospital discharge planner or case manager, a health care provider in the community, a member of the clergy, a social service provider, or even

the local Area Agency on Aging. Even when services are accessed, obstacles to the optimal use of the appropriate services may continue to exist.

Even though these challenges will always exist in some fashion, we have opportunities to improve the situation and empower consumers in the process of seeking home and community-based services as well as other services for older Americans. When designing policies and programs to educate, support, and serve seniors, it is important to consider the goals of the program. Aging is a process. As such, education about aging needs to be interspersed throughout the entire life span. As an aging society, we need to be more aware of what lies ahead for all of us and what resources are available— before the inevitable crisis occurs.

We need to understand that eventually we all will be care recipients at some point in our lives— some sooner rather than later. Early intervention and planning is key. Looking to the future, we all should evaluate our long-term care options and legal and financial issues well before the need arises. Advance directives, powers of attorney, wills and the like will minimize problems later on. After this analysis is finished, it is important to communicate personal preferences to those likely to be involved in future care decisions.

Outreach and education should take place at all the various points of entry. Information also should be available in places in the community where older Americans and their caregivers would most likely gain access. We should be mindful that caregivers and older people tend to seek information from different sources. For example, caregivers who are young might not always think of contacting a senior service organization, rather, they might look to the Internet. Support and information must be available in different venues so that older adults and caregivers will have access to information, which is an essential part of the decisionmaking process. We do a fine job of educating consumers about chronic illnesses; however, given the demographic shifts our nation is facing, we must try to do just as good of a job educating Americans about the various long-term care options open to seniors and their families.

Although a wide array of services exists in the community to maintain and improve the quality of life for older Americans, it is important for this Committee and all of us to continue to seek strategies for improvement. NASW appreciates the opportunity to come before you this morning and we look forward to continuing to work with the Committee as it pursues it's mission. Thank you and I am happy to answer any questions the Committee might have.

The CHAIRMAN. Our final witness will be Major Kevin Stevenson, who is from up here in Maryland. We have got some traffic problems out there, but he is here and he is on time and he is here. His parents happen to live in Napoleonville, LA. His mother is 73, and his father is 76 years of age. We have heard their story before, but we just asked Major Stevenson to share his thoughts with us on the problems associated with trying to find the right type of care for his parents. He is a typical example of children who live hundreds and maybe thousands of miles away from their parents and the challenges associated with providing long distance help. Major Stevenson.

STATEMENT OF MAJ. KEVIN STEVENSON, SILVER SPRING, MD

Maj. STEVENSON. Chairman Breaux, Senator Wyden, I appreciate the opportunity to actually come here today and provide testimony to the committee.

First of all, I would like to say I am also an Army social worker officer and I have been in the Army now as a social worker for 11 years. The services that have been spoken of in regards to what social workers do provide in the statement made by the NASW, we provide services to the elderly, also, be it retirees as well as their family members. We provide discharge planning services as well as medical and counseling services to them. So I do support what NASW is saying in regards to what we do and the challenges we have as social workers.

Again, I thank you for the opportunity to be able to provide testimony on behalf of my mother and father because they are not alone. Other citizens throughout the country request in-home long-term care assistance.

My father has been ill since 1995. My mother began requesting in-home services as of that year for my father. She began her request in seeking services first with home health care, the Council on Aging, and the Veterans' Administration. The Council on Aging were able to provide daily lunch meals for my father. Home health care provided short-term services for periods of time.

My father has been bedridden now since May 1998. He has been hospitalized at least three times in the last years, and in May 2001 was his last admittance to the hospital. He was admitted for gall bladder surgery. After his surgery, full recovery was questionable, but I thank God that he survived.

After each hospitalization stay, he was eligible for home health care services at a minimum of 2 to 6 weeks. We are told on each occasion, because care for him is so well provided by the family, and he has no bedsores or any other sores, no extra care is needed, and home health care services are discontinued and stopped.

Caring for my father has not been easy. My mother has hired an in-home nurse aide to come every morning to actually bathe my father. Recently, the Family Caregiver's Program granted services to my mother and father, as of February 2002, and it ended in June 2002. Then the services were renewed in July 2002 and are now extended to June 2003. This service only provides 9 hours a month.

My mother also gets help from her youngest brother and his wife, who live on the other side of Highway 1 in Napoleonville, LA. If it was not for my mother's brother, family friends, church mem-

bers, and other relatives, I do not think my mother would be able to do it by herself.

When I go home on leave, my main reason for being there is actually to support my mother and father. I would really like to have the opportunity to visit other friends and family, but I am there for her and providing respite care so that she may rest and do other things that are needed.

I would like to be able to at this opportunity to provide you a picture of what a day in my mother's life is like. At 5 a.m. in the morning, she wakes up, and about 5:30 each morning, 6:30 here, as I travel to work, I give her a call to find out how she is doing. At 7 a.m. in the morning, she gives my father his medicine and she changes his feeding tube.

At 7:30 a.m., the nurse's aide comes in and bathes him. Now, I would like you to be able to understand that my father weighs 195 pounds, and as a person lays in the bed and they are bedridden, that is basically dead weight and it is not easy for the nurse's aide or my mother to actually bathe him, but they have been doing that.

At 3 p.m. in the afternoon, my mother tests his blood sugar again and gives him his medicine. At 6 p.m., he gets another bath, and the bath that is given to him at that time is provided by the other caregiver. She provides a bath to him on 3 days a week and my mother actually bathes him in the evening 4 days a week. At 10 p.m. in the evening, she tests his blood sugar again, and then he gets medicine for the last time in the evening.

This is just one story of many other Americans that are wanting to be able to provide care in-home to their family members. I support this committee's efforts and I will continue to support my family in providing in-home services.

I would just like to also say in conclusion, we have to be aware, and I am clearly aware, not only as a social work officer in the United States Army but also as a citizen of the United States, that when I get older, I would like to be able to have in-home care as an adult myself, being able to be provided by my family and friends. Thank you.

The CHAIRMAN. Thank you very much, Major. I thank all of the witnesses for being with us.

Ms. Allen, let me start with you. Your survey has indicated that, unlike Medicare, for instance, where there is pretty much a standard national policy for all 50 States, Medicaid is different, with Medicare, all seniors, 40 million of them, approximately, have the same standard of care but when we talk about Medicaid providing help and assistance and cooperation with the States, we are finding that in the four States you looked at, which I think is probably true for all States, you have 50 different sets of rules and standards about what can be done and what cannot be done in dealing with long-term care, which Medicaid becomes one of the principal providers for.

I think that in the States that you looked at the variation was pretty dramatic. Do you agree that it was dramatic or do the data compare with a little bit of tinkering around the edges?

Ms. ALLEN. There were some commonalities, but there also was extreme variation across the States. But what was also interesting, sometimes it was not just a matter of that State's policies. Some-

times we saw even in the same community that two case managers seeing similar people would prescribe very different approaches to care. So the variation also is very dependent on who the individual case manager is and what he or she thinks is necessary to meet that set of needs.

It gets right back to the point that Major Stevenson was making, that people have a lot of different needs, and often, there has been an ethic in our country that families help take care of their own families. About two-thirds of all people who need long-term care in the community are supported by their families.

But as Major Stevenson pointed out, family caregivers need respite. They need help, and we saw that play out through our case managers. Again, two case managers in the very same community could offer very different services depending on what he or she thought would be necessary to best serve that family's needs.

The CHAIRMAN. Do you think that is because of a lack of information and knowledge among the case workers as to what is available? Is that part of it? I take it that it is due more in part because of what is available within a State. I think the testimony from Ms. Broussard was that 80 percent of the care expenditures in my State of Louisiana are covered under Medicaid. Medicaid is responsible for 80 percent of the nursing facility care in our State. It seems like there is a huge bias for institutional care in nursing homes in Louisiana.

So why do you think the variation exists? Is there not enough flexibility? Talk about Louisiana for a bit as to what you found with regard to how the money is being spent and what type of waivers we have down there.

Ms. ALLEN. All right. In Louisiana, as you pointed out, the vast majority of the long-term care spending is going to nursing home care. Over 90 percent of the long-term care dollars for the elderly, the Medicaid dollars, are being spent on institutional care.

The CHAIRMAN. Over 90 percent?

Ms. ALLEN. Ninety-three percent, by our calculations. Louisiana does have two waivers that help meet the needs of some individuals, as Ms. Broussard pointed out. But the numbers that are served are rather limited. I think she mentioned that there are about 1,800 slots with one waiver. There are about 5,000 people on the waiting list, and as she pointed out, one of the explanations is they encourage people to go on that waiting list even if they do not qualify financially at this point in time, because over time, they will.

Another waiver that Louisiana has deals with adult day health care, which is a little different from some other States. In some other States there are different models of adult day care. Some focus on social services. The one in Louisiana, it is our understanding, has more of an emphasis on health care services. So they are trying to meet a higher level need. For that waiver, our understanding is about 500 people are being served and about 200 people are on the waiting list.

The one other thing that I would mention as far as Louisiana is concerned is we found that there is a cap on the amount of money that a case manager can spend per individual per day. That cap was about $35. That $35 will not go very far in terms of paying

a caregiver to come into the community. That cap is a factor of the limited number of slots that have been funded as well as how much money has been allocated for that, and that is in stark contrast with some other States we have looked at where there are not similar caps.

The CHAIRMAN. Do you have any thoughts about what would happen if Congress decided to move toward not requiring the waivers? I mean, this whole process where the State has to come to Washington and ask to do something that is in their best interest and they probably know better than we do, to just have something that would not require the waiver process? Rather, just make services available in to the States as long as they are meeting certain standards with what they do?

Ms. ALLEN. Mr. Chairman, there is a provision in the Medicaid program now that would lean in that direction, and would not require a waiver. There are certain things in the Medicaid program that are mandatory services. Nursing facility care is one of those. Home health care is one of those. Those mandatory services, though, are often contingent on the income eligibility level that a State sets. So if the income eligibility level is set very low, it is possible that not very many people would qualify.

But there is another option within the Medicaid program, what is called optional services, and personal care is one of those optional services already set up in statute that a State can elect to fund and cover. If they elect that option, it means that those services will be available to everyone across the State with no limits on the number of people served except, again, that they can set the income eligibility levels which will somewhat control the thresholds.

The CHAIRMAN. Would that cover home health care as we know the services now?

Ms. ALLEN. Well, home health care is a mandatory service, which will be more of a skilled service. Personal care is one thing that others have talked about this morning. That would be the hands-on bathing, feeding, some of the other things that some would say are more custodial care.

Now, the issue, though, is that more than half of the States have picked up the personal care option, but it is still not a large part of the funding. I think it comes down, again, to where do States choose to put their dollars and how are they trying to constrain costs overall.

The CHAIRMAN. Ms. Broussard, you mention in your testimony that Medicaid is responsible for 80 percent of the nursing facility care, and then you heard Ms. Allen say that, what, 93 percent of the, what, State money that is being spent——

Ms. ALLEN. Medicaid long-term care spending is on nursing homes.

The CHAIRMAN. Why do you think it is so high? It is probably the highest in the nation, I would imagine. What is happening down there? I mean, why have we not looked at other options more aggressively? I have always told the nursing homes they ought to be in the business of assisted living and in other businesses that provide this care. We started off sort of like we did with Medicare in

1965 with a bias toward hospitalization, but things have changed. This is not 1965 and there are other alternatives.

I have always told the nursing home industry that they are missing, just from a pure economic standpoint, a good avenue of increasing business by moving into other types of care; assisted living care, long-term care in community-based settings, home health care. Ninety-three percent is just an incredible amount. Can you comment on why?

Ms. BROUSSARD. If I had that answer, we could probably provide more services to individuals. I know that we started the Medicaid waiver in 1993 in Louisiana and we started out with 500 slots, and we have had a battle in the State legislature to get it up to—we are now funding 1,200 slots and there are 525 of the ADHC, the adult day health care waiver. It has been an uphill battle. We currently provide case management, our agency, for the waiver program.

The CHAIRMAN. What is the argument used against it? I mean, why is it a battle? When someone disagrees with that, what do they say?

Ms. BROUSSARD. We have a very strong nursing home lobby in Louisiana and you are taking money out of the nursing homes to put it in in-home care. The argument is that it costs more for care for individuals at home because we do have to—and it has increased to $55 a day, that we have gotten an increase in care. But then they throw in, well, but they have to go to the doctor more often. When you are in a nursing home, the doctor comes to them. So we have all these issues that we continually battle.

I think taking care of someone at home is definitely where we need to be. I have been doing these programs for 20 years and I can say that when I started 20 years ago, there has not been much change in what we as agencies do with the Older Americans Act. We have gotten a few new programs, the Caregiver Program. We were just totally excited for that because we can start to get into that arena of providing care for caregivers. But we still cannot get the medical end to people who want to remain at home. We can provide the supportive services, we can provide the nutrition services, but there are some services that agencies such as ourselves cannot, and I wish I had the answer as to why.

The CHAIRMAN. I think you gave the answer.

Ms. BROUSSARD. Well, maybe——

The CHAIRMAN. You gave it very well.

Ms. BROUSSARD. Oops. [Laughter.]

The CHAIRMAN. I think that people are missing the boat. I do not want to be repetitious, but in order to make the point, I will be. I think that institutional caregivers are missing the boat economically and not moving out into other areas of home health care or helping in assisted living facilities. I mean, that is where the future is. Providing solely one type of institutional care is where the past is.

Just like Medicare in 1965 which was created and is outdated today needs to be reformed and brought into the 21st century, so does the whole concept of how we treat our aging population. The population today does not want to be in an institutional 24-hour-a-day, 7-day-a-week care facility if it is not necessary. Now, for

some, it is necessary, and thank goodness they are there. But for many, they are there only because of a bias on behalf of States. Many are there because it is the only thing that is available. That is the real challenge and what we have been trying to emphasize with this committee.

Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman. All of you have been very helpful.

Let me begin, if I might, with you, Ms. Allen. Do the residents of the State of New York, a State that spends nearly three times the national average per capita, do they get better care than those in Oregon, which is now spending two-thirds of the national average?

Ms. ALLEN. Senator, I am not sure I can respond to that question. We did not look at quality as a part of this study. I will say, however, where we have another study in process, we are looking at exactly that question, the quality of care that is provided in home and community-based settings.

We do know in the course of the work that we are doing there, which builds on work that we did a few years ago for this committee also on assisted living that included the State of Oregon as well, that there are concerns about the quality of care in home and community-based settings. What we find increasingly is that many of the individuals had the same care needs that you will find in a nursing facility. I think Major Stevenson described some of those today, a lot of needs. The services in these settings are often less regulated than they are in nursing homes.

So we hope to be reporting on that very shortly. But in the course of this study, Senator, we did not look comparatively at the quality of care.

We can say, though, that we saw some differences in terms of the number of hours of care. For example, in the State of New York, as well as Oregon, there was a strong bias, I should say, to try to provide around-the-clock care to an individual in their home if that was what was needed. In those situations, though, we found that one of the constraints was finding the home care workers or the aides who would be willing to provide that care, particularly in the night shift. So the supply of workers is sometimes a constraint in being able to meet those needs.

Senator WYDEN. I was trying to keep from pinning you down on the quality question because I know that your study was not to be determinative on the quality issue, but at least at this point, you think that one of the drivers behind these variations involves the number of hours somebody gets care, access to trained workers. That would be at least your judgment up to this point, prior to your report on quality?

Ms. ALLEN. Yes.

Senator WYDEN. All right. Given, Ms. Allen, this huge variance in care plans, what are your recommendations for the committee to make sure that consumers and families can find the best treatment for them?

Ms. ALLEN. I think the best thing to do is work through, to begin with, with the local AAAs because I think that they are a wonderful catalyst for trying to pull together the services that are avail-

able. Also, to the extent that people are aware of what they may qualify for is helpful.

One example is Medicare home health. To be candid, we were a little surprised that in some situations in some States, even in the same community, that a case worker may build the Medicare home health into the care plan, saying we will help you get this or make sure you talk to the physician and have this prescribed. In some cases, this was a way to conserve Medicaid dollars. Medicaid is supposed to be the payer of last resort, so they would say, "we are going to help you get Medicare home health so that we can provide you with other things that would not qualify for Medicare."

But in some cases, the case worker did not do that. So in that respect, to the extent that an individual is aware of what they qualify for, and again, I think that going through social workers and AAA they can get assistance in knowing what they do qualify for.

Senator WYDEN. That sounds pretty troubling. Are case workers trying to save money? Are case workers unaware of this extra opportunity to serve older people? What was your sense behind that?

Ms. ALLEN. Well, in some situations, I will say that we were in somewhat of an artificial situation in terms of our hypothetical individuals. We conducted our work over the telephone and clearly identified that we were the General Accounting Office and what we were doing. It is our understanding, though, that most of the time there would be a face-to-face interview between the case workers and the individual, and perhaps with that face-to-face, that there would be more exploration of what is available and what is not.

Sometimes we would prompt the case worker, once she had finished talking through the services available, well, is there anything else available, for example, Medicare, and she would say, oh, yes. Oh, yes. I simply forgot to mention that, but obviously, of course, that is available.

Senator WYDEN. How often did that happen?

Ms. ALLEN. For Abby, the 86-year old woman with debilitating arthritis, case managers referred her to Medicare and/or Medicaid home health services in 14 of the 16 care plans developed for each of the three scenarios we presented. In the other 2 care plans, home health care was not recommended or, in two scenarios, a care plan recommended a residential care setting rather than in-home care.

For Brian, the 70-year-old man with Alzheimer's disease, about half (7 or 8) of the care plans recommended Medicare or Medicaid home health in the two scenarios where Brian lived with his wife. The other half did not include home health care services. In the scenario where Brian lived alone, only 3 case managers would recommend that Brian remain in his home. Of these 3 case managers, 1 recommended Medicaid home health services and the other 2 recommended round-the-clock in-home care but did not mention home health care.

Senator WYDEN. The coverage, as you know, in some places is so limited that if on top of that we have case workers who are not being aggressive and proactive in terms of telling patients and families what their options are, that is sort of a double-whammy on the

country's older people. So I would really be interested in knowing how often that happens.

One last question for you, Ms. Allen. Did you find that State mandated cost restrictions were influencing health care plan recommendations?

Ms. ALLEN. There was a sensitivity to resource constraints in two of the States that we went to. In the States of Louisiana and Kansas, there was an understanding that there were limits overall on resources and so there were attempts to maximize the number of hours possible, but recognizing there were constraints.

That was less true in Oregon and New York. There seemed to be many more resources available, partly because there was more being done under the Medicaid State plan itself with no limits on the number of people served. Now, there were some considerations in terms of budget neutrality, that the waiver services could not exceed the cost of what a nursing home would be, so that was somewhat of a constraint. But we did see some differences across the States in terms of what they could answer.

Senator WYDEN. Ms. Broussard, I have always felt that the key to making the aging network work and maximize its potential is all of you the Area Agencies on Aging. I mean, you all are the front lines and it is an extraordinary service you provide. What is the service that older people now want the most when they come to the AAAs?

Ms. BROUSSARD. Most of them—our meals program is a pretty infamous program. They always say, well, I need a meal-on-wheel, so we send them meals-on-wheels. But that is generally one of the things. They can get a hot meal at lunch.

We also, we are starting to get now more and more, I want to stay home but I need someone to help me stay there. So now, we are getting into that. Where we used to be able to provide homemaker services, where someone would go in and do some light housekeeping and they would also get a home-delivered meal. So now we are finding that those are still key services, but we are going into the caregiver realm, now that family members are calling and wanting care for their family.

Senator WYDEN. What kind of waiting list do you have for your key services?

Ms. BROUSSARD. It depends on the parish, county.

The CHAIRMAN. Parish. [Laughter.]

Ms. BROUSSARD. Parish, yes. We have in our urban parish, which is Lafayette Parish, approximately 300 to 400 people on the waiting list for home-delivered meals. In some of our smaller parishes, you are looking at 150 or better. Over the past 10 years, we have had a decline in the number of services that we could provide simply because the population is growing but the dollars are remaining the same.

So we have had to do some things at our agency so that we could at least continue to maintain a level where we are comfortable that we are still serving a good bit of our population and that is by going into sliding scales for paying for our meals program, where every 5 days we could pay a different price for a meal based on the number of meals we serve. So we have had to do some creative things at our end to keep the services up, and——

Senator WYDEN. Have you seen in the last 6, 8 months with some of the economic concerns that people are volunteering less when they come to the programs? My sense is that a lot of the older people, the combination of the prescription drug increases and maybe they would have a small CD or something as a little bit of a cushion and now they are not getting much on that, that we are really seeing a drop-off in the capability of people to put that voluntary contribution in.

Literally, since I was Director of the Gray Panthers, that was something we always watched because it was a measure of how older people were doing and out-of-pocket medical costs and the like. Have you all seen that drop-off in terms of what people are giving on the voluntary side?

Ms. BROUSSARD. We have seen a drop-off, mainly with our homebound individuals. The thing with an individual going to a site to eat, their peers are there so they will tell them, oh, you passed up the box, so they will go back in and they will drop a dollar or a couple of coins into the box. So peer pressure in a group setting, it can kind of—it has leveled off, but our home-delivered individuals, our home-bound people, we have seen a slight drop-off.

But, you know, we have always pushed and told them that if you can give, then we can serve your neighbor. So we have tried to keep the education level up on what we do with the contributions and we have also gone to families, too. We will send them the same letter that we may send to one of our clients so that the family knows that if you can help your mother volunteer or what have you, then maybe we can serve someone else.

But there has been a slight increase, plus in Louisiana with the gambling industry, we find that a lot of our seniors do like to go, so—— [Laughter.]

It is an outing for them. They play the nickel machine, but it does have an effect on what they can give. But we are not an entitlement program. The Older Americans Act is not an entitlement program, so it does not matter if—you could be sitting next to someone who is a millionaire and it does not matter in our programs, which is good with Older Americans Act programs. We treat everybody the same. You just have to be 60.

Senator WYDEN. My time is up. Major Stevenson, as you know, the aging network of services and home and community-based services is kind of a crazy quilt and it is hard to follow. The fact that you are tracking and navigating with your folks' system is exactly what we are hoping our generation will do, so three cheers to you. I know the navigation of the system is difficult but it is important that you be here to tell us your story.

Ms. Yagoda, we have worked with your organization many times over the years and I just thank all of you for being such good advocates for seniors.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Lincoln.

Senator LINCOLN. Mr. Chairman, first, thank you for your leadership on all of these aging issues. Chairman Breaux has just been an incredible force in helping us in the Congress focus on the issues of our aging parents and our aging populations and constituencies we serve and we really appreciate the work. It is now, I

think, 14 hearings in the Aging Committee that we have had on this subject.

I am very happy to learn once again from the chairman and the ranking member, that October 1 through 7 is Long-Term Care Awareness Week, which gives us all an extra opportunity to bring about a better awareness of the need to take care of our aging parents and our aging population. We thank you, Mr. Chairman, for all that you do.

I apologize for being late and not getting to hear your testimonies, but I am delighted to have an opportunity to ask you just a few questions. One of my concerns regarding long-term care is some of the Medicaid bias toward institutional care, and I know you have talked a little bit about that. Most people needing long-term care do prefer to stay in their homes or their community settings.

With aging parents myself, I know that my parents were childhood sweethearts. My mother is going to do everything she possibly can to keep my father in our home, and if it is to the detriment of herself, she is going to do that. It does not matter how much my sisters, brother and I try to tell her that she has to look after herself, she has to take care of herself, what if she falls, it does not matter. She is going to do everything she possibly can to keep him out of an institutional setting as long as she possibly can.

That is why it is also so important, not only for those that we are caring for but those who are caregivers, who put an undue hardship on themselves in order to make sure that they are doing everything they possibly can for their loved ones, and so we do want to check on doing what we can.

Arkansas has been successful in getting some Medicaid waivers to allow the State to pay for long-term services in-home and some of the community-based settings for people who would otherwise need institutional care, and Arkansas has used this waiver to set up their Elder Choice program, which has been successful.

But the waiver option applies only to people who would otherwise be institutionalized, and you have mentioned that. What about the people who are not at the point of needing institutional care but still require long-term services and would like to remain in their home and their community? We want to be able to work hard to try and solve that question for our constituency.

We are also concerned about the options that are available to the middle class. Obviously, Medicaid through its waivers and institutional opportunities provides long-term care opportunity for the neediest, but there are those that are just over the line in terms of Medicare and we want to make sure that we keep focused on that.

Ms. Allen, in your GAO study, you only include those four States, and I know you have talked about that. Based on your experience and research, and you may have already touched on this, would you say that poor or rural States like Arkansas have fewer services available? Is there a rural nature to this problem? I look at Kentucky, Louisiana, New York, and Oregon. Out of that study, do you have any sense for what rural States go through, more so than others?

Ms. ALLEN. We did not look specifically at rural versus non-rural States, but what we did do in the course of our study was to make sure that we selected two different communities in each state, a large and a small, in order to look, and I would say that our findings are consistent across those both large cities and smaller cities. In each State, we chose a city with fewer than 15,000 people, and we did not discern really notable differences in terms of the types of care plans that were being prescribed. So I would not say that the approach that we took, we necessarily saw that.

Senator LINCOLN. Maybe sometimes it is just that services are more difficult to provide in rural areas because you have got, obviously, an enormous transportation barrier and challenge that you have got to face.

I am curious to know, other countries and what long-term services other countries offer. Is there anything that you can expand on that they are doing, suggestions or ideas or things that you see in other countries that could be adapted to better use here?

Ms. ALLEN. I wish I could comment on that today, but I am afraid that I am not in a position to do that.

Senator LINCOLN. OK. Ms. Broussard, just in watching in my own family and understanding that women tend to live longer than men and usually end up being a caregiver, in most instances they often end up living alone at the end of their lives because they have been a caregiver, are there any efforts underway to see that older women get priority in some of these services? Do you see that at all?

Ms. BROUSSARD. Gender has no factor in any——

Senator LINCOLN. Pardon me?

Ms. BROUSSARD. Gender does not have a factor that I am aware of.

Senator LINCOLN. But clearly, do you see——

Ms. BROUSSARD. Oh, certainly. The majority of the people that we serve end up being people who live alone, they are mostly women, they are very rural, and they are mostly poor.

Senator LINCOLN. Mostly poor?

Ms. BROUSSARD. Mostly poor, yes, which the older men tend to like, too, so—three-to-one, so——

Senator LINCOLN. They like those odds. [Laughter.]

Of the services that the Cajun AAA provides, which one has the largest impact on rural residents, do you think?

Ms. BROUSSARD. The largest impact would be our in-home services, and that is our home-delivered meals and our homemaking services, as well as some transportation services, because a lot of an older person's problems stem from not being able to get from point A to point B.

Senator LINCOLN. Right.

Ms. BROUSSARD. So we do have a number of our parishes that are big transportation providers. They also get 5310 money, which is through the Department of Transportation, and 5311 funds. So we try to get them out instead of keeping them at home, because that way they can visit with people, and when the mind continues to be used, you continue to go a little bit further. But our home-delivered meals, meals-on-wheels, is still one of our big services.

Senator LINCOLN. Well, you are exactly right. The stimulation is important. My husband's grandmother is going to be 105 on Monday, and if the car is started, she is in it. She is ready to go. She wants to be out there with people and doing all kinds of things.

You mentioned when Senator Wyden asked about a waiting list, you mentioned 300 or so. Do you find that you have faith-based organizations locally that try to pick up the slack of those kind of situations when you do have waiting lists, or do your faith-based or your nonprofit groups participate in really making that happen?

Ms. BROUSSARD. Well, we have in our Lafayette Parish, which is an urban parish, we do have churches that volunteer to help us deliver some of our meals, so it helps us in the administrative end by having volunteer organizations helping us with the delivery.

As for providing food sources and what have you, we have had some of—we have St. Joseph's Diner. We have a few diners that will kick in around holiday times. But we are mainly the program, you know, our meals-on-wheels program and our congregate meals program.

Senator LINCOLN. Well, I remember I participated in one of our meal delivery program one time and I realized, like you said, the home care needs, because every home I went into, they wanted to visit. They wanted to sit down and talk. But they would say, well, can you change that light bulb for me before you leave, and so I got my youth group at church and we spent one Sunday a month going into some of the shut-ins from the church and doing just some of those little tasks. So it is important to know that everybody can work together.

Major Stevenson, I want to give you accolades and compliments. As a child of aging parents, I am back in Arkansas a good bit, but I am here an awful lot and it is very difficult from those distances to really be able to feel comfortable in what you have been able to do. So I, like the chairman and Senator Wyden, want to compliment you on the fact that you are navigating these systems and really looking for the ways that you can find different agencies and other groups that can be helpful to your parents in their aging years. It is definitely challenging, and as a child living in a different part of the country most of the time, I certainly can identify with you.

Just a couple last questions. Ms. Yagoda, just to touch a little bit about those that are just above the poverty level, what services really are available for them, those that are just above the poverty level that do not qualify for Medicaid?

Ms. YAGODA. It depends on the jurisdiction where they live. It depends on what their needs are. A lot of the services that are available are the services that Ms. Broussard talked about through the AAAs, the home-delivered meals, the chore aides——

Senator LINCOLN. They are not dependent on income?

Ms. YAGODA. That is right.

Senator LINCOLN. But is it mostly all available through the AAA?

Ms. YAGODA. The non-health-related services?

Senator LINCOLN. Yes.

Ms. YAGODA. The more social services? Yes. Then the more medically related services would probably be available through Medicare.

Senator LINCOLN. I am just wondering, I hear you all talk about Medicare home health. There must be more available through Medicare home health than I am aware of. Not a lot?

Ms. YAGODA. Again, it depends.

Senator LINCOLN. Is that right?

Ms. YAGODA. It depends on the need and the diagnosis and the skill level.

Senator LINCOLN. What do you see as the most fundamental need for that near-poverty group?

Ms. YAGODA. There are so many. I think part of it is what we are discussing today. Where do they start to get access, education on what is available.

Senator LINCOLN. Right.

Ms. YAGODA. I think that knowing how—to have an advocate to know how to navigate the system. A lot of people do not know where to start. They do not know where to begin. They do not know, should they call Medicare first? Should they call the AAA first? Should they go through their doctor? That is a biggie for the——

Senator LINCOLN. Where to start?

Ms. YAGODA [continuing]. For the care recipients and the caregivers, where to start.

Senator LINCOLN. Education is clearly important the Robert Wood Johnson Foundation did several studies in Arkansas and they found that there were actually more services than people realized. The biggest key was for people to be educated on what was actually available to them and how do we get that information out, how do we educate them to let them know what is available, how they access it, and where they continue to go to—as they age even more, where do they go to get more of those services.

We thank you all very much for being here. I apologize for being late, but we have a wonderful chairman and he keeps on top of this issue and makes sure that we are all focused, so thank you very much.

The CHAIRMAN. Thank you, Senator. I think that with regard to what you are talking about, Blanche, this little card we developed really helps. We are going to have it on our Aging Committee website. It really tries to give people first information a first stop for services, and provides information about who to call, and list some of the places they can call to find out what is available. On the back of the card we try to give guidance as to the steps to take in order to prepare for the search and what information a consumer should know about themselves or their loved ones. Hopefully, this card will be somewhat helpful to the people out there.

Senator LINCOLN. Does Social Security put anything like this in their mailings that go out regularly?

The CHAIRMAN. I do not know the answer to that question. I have not seen anything that specifically deals with something like this. I think that, mostly, those mailings provide mostly just information on Social Security, how much the taxes are and how much the individuals owes. Maybe I am wrong, but it would not be a bad idea to work with the Social Security Administration because they contact every single person in the country, I would like them to mail this out with every Social Security mailing.

Senator LINCOLN. Ms. Broussard.

Ms. BROUSSARD. I would say that we get a lot of referrals from Social Security, that Social Security told me to call you. So they obviously, in our area, they will instruct them to come to us.

Senator LINCOLN. It looks like it would be worth it to put one of these in their Social Security mailing.

The CHAIRMAN. Put them in with every check that everybody gets in the mail. If Social Security would have something like this, it would be, I think, very helpful. We will have to take that up.

Senator LINCOLN. Even if they just did it once or twice a year.

The CHAIRMAN. Yes. They do not have to do it every time. It will be the Lincoln proposal. I think it is very good. [Laughter.]

Major, thank you very much. Any suggestions for what you think the committee can do? I mean, you have always been very helpful talking to us.

Maj. STEVENSON. I would just like to be able to say this. In regards to what services are available or who knows where to begin, a lot of times, it is starting where the client is, meaning allowing them to tell you what services they would like to have, and then at that time, making sure they can make those services available.

We talk about, you know, the fact that it is not gender specific or anything like that. Most times, it is looking at the income. I can tell you from my parents and from my mother in regards to respite care, wanting to have that service available, a big issue is the medication. When you look at the income that they are receiving, the things that they are having to pay for and just being able to make ends meet each month, it is being crunched up by the medication. Her just wanting—it is not a whole lot, the support with the medication, the support with having someone come in and at least bathe him for a little while.

What is very interesting to me, and I am sure other elderly, is the fact that they would say to my mother, and I am sure others, we could pay, just as others have been saying here today, we can pay for you to go into the nursing home. However, to continue the in-home care, we cannot do that, and the question is, well, why? Well, this is just the way it is.

I can tell you, I think it would be more cost effective with the services that have been provided to my mother in regards to coming in and at least providing the care of bathing him, someone being there at least for a couple of hours for her to go and pay bills and things of that nature, would be a big start. But yet, it is very ironic that they would say, let us put him in institutional care and we cannot provide the small time that is being asked for. So if we could do that, that would be an issue.

The CHAIRMAN. That is a very helpful suggestion and very well said.

I would like to thank all of you for being here, particularly Shannon for coming up from Louisiana, and all of you for making a real contribution here. That will conclude our hearing today.

[Whereupon, at 11:16 a.m., the committee was adjourned.]

APPENDIX

Grannie Mae

TESTIMONY FOR THE RECORD

SUBMITTED TO

THE U.S. SENATE

SELECT COMMITEE ON AGING

BY

GRANNIE MAE
(Global Family Resources, Inc. d/b/a Grannie Mae)

Washington, DC
October 10, 2002

1101 Pennsylvania Ave., NW • Suite 700 • Washington, DC 20004 • *Telephone:* 888.440.4676 • *Facsimile:* 202.756.7554 • www.grannicmac.com

Chairman Breaux:

Thank you providing this opportunity to submit testimony for the record on behalf of Grannie Mae. I am proud to introduce to you and the other Members of Congress, Grannie Mae - the pioneer in elder care family financing solutions.

The concept for and subsequent development of this long-term care financing program was born out of personal circumstance and a tremendous desire to develop a private financing system that would enable non-Medicaid families and patients to access the full continuum of long-term care services--something most Middle Americans today are unable to do simply because it is cost prohibitive. We believe that Grannie Mae is innovative, affordable and, importantly, preserves the dignity and independence of the elder. We also believe that when the data is in, this program will significantly reduce the federal and state financial burden for some of these services.

Mr. Chairman, Grannie Mae has recognized the financial crisis facing middle-income families of elders requiring long-term care and has responded. We hope to participate in current and future debates on this matter as Congress considers the many different alternatives to addressing national long-term care crisis

BACKGROUND

Our nation is in crisis when it comes to the issue of long term care. In increasing numbers, American families are faced with the challenge of caring for their elders. Typically the need for long-term care arises out of a crisis-driven event such as a fall or health condition and calls for quick decision making in an unfamiliar environment and with little or no advance planning. Families have an immediate, urgent need for *liquidity* to pay for the significant cost of long-term care. When families do settle on a care option for their elder, they frequently discover they can't afford it. This is especially true for middle-income families many of which have two working spouses and children in college.

Today, there are 32 million elders over age 65 in the United States – a number that will increase significantly over the course of the next 30 years. In fact, it is estimated the aging of the Baby Boomers will more than double that number to 79 million by 2030. Eight million people require some type of long-term health care. A steady increase in longevity and in the elderly population has led to a rise in the number of Americans likely to need some form of long-term care.

The cost of nursing home care is expected to rise from an average today of $46,000 per year to $97,000 per year by 2030. Unfortunately, most people are under the impression that their personal health insurance covers long-term care costs. It doesn't. In fact, public coverage for long-term care today is provided mainly through the federal Medicaid program and that primarily covers nursing care costs NOT assisted living and other important community based services such as home health care and respite care costs. In limited instances Medicare provides long-term care coverage.

Because the resources of middle-income elders are limited, they are often forced to deplete their personal assets and eventually rely on Medicare and Medicaid for services, forfeiting the right of

choice of providers and services and often being placed in a health care setting that is inappropriate.

Only wealthier elders can afford to pay the full cost of long-term care costs associated with assisted living/care scenarios. The remainder of the LTC population relies on Medicaid and Medicare to cover the cost of their care but such coverage is limited to specific medically-oriented needs and services. Elders pay out of their own pockets or more likely rely on adult children/family to help finance the cost of care and services that Medicaid does not cover.

When the elders' resources have been depleted, adult children are often called upon to provide financial support for long term care services. On average, each adult child spends $19,525 in personal out-of-pocket expenses for their elder's care causing tremendous strain on a family's long term finance according to a recent MetLife Study. Additionally, the estimated aggregate costs of care giving in lost productivity to U.S. business is $11.4 billion to $29 billion per year.

On average, each adult child spends $19,525 in personal out-of-pocket expenses for their elder's care causing tremendous strain on a family's (adult children's) immediate cash flow, according to a recent MetLife Study. The current generation of adult caregivers is being "sandwiched" by its need to provide higher education to their children in addition to having to care for elder parents, further impacting a family's monthly cash-flow.

On average adult caregiving children lose approximately $659,000 in wage wealth, pension and social security benefits due to lost work time spent caring for an elder according to that same MetLife study. Additionally, elders are often forced to deplete their personal assets and eventually rely on Medicare and Medicaid for services, often forfeiting the right of choice of providers and services and often having to place their loved one in a health care setting that is inappropriate.

It is in the face of these challenges that Grannie Mae has been created. Grannie Mae will provide an affordable, flexible and effective private financing alternative families in need of immediate financial support to meet long tern care needs of a loved one. We hope that the Congress will view Grannie Mae as a partner in the debate surrounding long-term care. Finally, we believe that Grannie Mae and its programs can and will significantly and positively impact the national debate on the most effective ways to address the long-term care crisis

GRANNIE MAE

Grannie Mae, established in 2000, is the pioneer in elder care family financing solutions. Grannie Mae has recognized the financial crisis facing middle-income families of elders in need of long-term care and has responded with the development of a viable financing alternative for families of elders requiring long-term care that is innovative, affordable and preserves the dignity and independence of the elder.

As you know, the resources of middle-income elders are limited and adult children of elders are often called upon to provide financial support for long term care services. That need is often in crisis situation and with little or no advance planning. The adult children have an immediate, urgent need for *liquidity* to pay for the significant cost of their elders' long-term care.

There are no federal, state or private programs that provide adequate coverage of long-term health care services. Our comprehensive credit lending program has created a number of new eldercare consumer financing plans specifically tailored towards the long-term care market place. Qualified families will have convenient access to *unsecured*, elder care lines of credit at reasonable-interest rates, ranging in size from as little as $3,000 and possibly as high as $50,000 (depending on one's credit-worthiness) without the complexity and hassle of typical lending processes.

Grannie Mae's comprehensive credit lending has created a number of new eldercare consumer financing plans specifically tailored towards the long-term care market place. The program provides families with multiple adult children convenient and immediate access to *unsecured*, elder care lines of credit at reasonable-interest rates, ranging in size from $3,000 to $50,000. Loans can be provided for services such as home health, adult day, care, respite care, assisted living care, etc.

Our comprehensive credit lending program has created a number of new eldercare consumer financing plans specifically tailored towards the long-term care market place. Qualified families will have convenient access to *unsecured*, elder care lines of credit at reasonable-interest rates, ranging in size from as little as $3,000 and possibly as high as $50,000 (depending on one's credit-worthiness) without the complexity and hassle of typical lending processes.

Our program will enable families with multiple adult children to take out multiple loans to share the financial burden – thereby avoiding the full burden being absorbed by one family member. Grannie Mae will offer loans based on the type of assistance that is needed such as home health, adult day, care, respite care, assisted living care, etc. and the family's ability to afford the care costs. We will work with prospective borrowers to determine the cost of care, the amount the elder can contribute and additional funds that will be needed to meet that monthly cost.

Our program will provide adequate funding for immediate and long-term needs while allowing families the benefit of time to make appropriate long term financial arrangements such as selling their elder parents' home or the orderly liquidation of other assets. Importantly, our program will enable adult children of elders to make the long term care decisions that are in the best interest of the elder.

Through this program, Grannie Mae will allow families the benefit of time to make appropriate long term financial arrangements such as selling their elder parents' home or the orderly liquidation of other assets. It will enable families to share in the financial burden and to make the long term care decisions that are in the best interest of the elder. Grannie Mae will return the power and flexibility of consumer choice to families and elders.

Grannie Mae will:

- Provide a nationwide directory of elder care support programs and services;
- Offer content on aging and wellness;
- Link families with elder care professionals; and,

- Enable consumers to research and purchase eldercare products and long term care insurance policies.

As a new entity, with a significant ability to assist in and advance the national debate on how to address the long-term care issue, we are asking Congress to support our efforts in the next several years in three key ways:

1. **$3 million in federal support.** This funding will enable the organization to:

    - *Provide the capital base necessary to encourage banks to issue the unsecured elder care loans Grannie Mae has pioneered;*

The Company, upon obtaining the above assistance to encourage the banks to issue elder care loans to families in need of liquidity with elders requiring long-term care can then:

- Finalize relationships with assisted living providers nationwide that will be partners in the program – 230 providers with 38,000 residents are waiting to offer Grannie Mae's flexible elder care family financing program;
- Design and develop educational and marketing materials for the public;
- Develop internal capabilities to service elders and their families seeking financing;
- Offer loans with in 45 days; and,
- Evaluate and disseminate information on program effectiveness.

2. **Assistance in obtaining designation as a Government Sponsored Entity (GSE) status**

3. **Long term tax deductibility for elder care loans**

CLOSING

Grannie Mae has developed a creative, flexible and responsive solution to long term care financing that encourages family responsibility and unity and preserves the dignity of the elder. Additionally, by providing this option to families we will delay and in many instances avoid the use of federal Medicaid program for these types of services, potentially providing a significant savings to that overburdened program.

As Congress strives to address this national need in the 107th Congress and beyond, Grannie Mae would welcome the opportunity to act as a partner in the development of sound long-term care fiscal and program policy. It is our mission to provide an innovative and effective approach to providing unsubsidized private financing to the families of individuals in need of long-term care services. This program will also empower patients and families to make the best decisions for their elders. For these reasons and many more, we believe the federal government should invest in this demonstration.

TESTIMONY BY THE SOCIAL SERVICES BLOCK GRANT COALITION

ON

THE ROLE OF SSBG IN ADDRESSING ELDER ABUSE AND LONG-TERM COMMUNITY BASED CARE

THURSDAY, SEPTEMBER 26, 2002

TO

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

The Social Services Block Grant Coalition: c/o Kathryn Dyjak, American Public Human Services Association 202-682-0100, John Sciamanna, Child Welfare League of America, 202-639-4919

The Social Services Block Grant (SSBG) Coalition representing a broad cross section of national, state and local human service agencies, policy makers, providers and charities is pleased to submit this testimony on the role of the Social Services Block in financing community based services for elderly and disabled persons. We are pleased that the Special Committee on Aging is holding a hearing on the importance of these services and the need for federal leadership. As you consider legislation to deal with some of the great challenges and questions surrounding how to most effectively address long term care needs, we hope this Committee will recognize the important roll SSBG plays in this area. We hope that part of your strategy will include a restoration of this block grant.

SSBG—An Important Funding Source For Services Supporting Elderly Persons and Persons with Disabilities to Remain in the Community

As the American population ages, the demand for social services to support the elderly is growing. However, with few federal funding streams of which to draw from, states have now begun to rely even more greatly on the Social Services Block Grant. For example, in a short three year period, the amount of dollars states used from SSBG for Services for the elderly in the community increased by 50 percent from $117,663,000 to $180,948,000. The most recent data on SSBG is the "Social Services Block Grant Program Annual Report on Expenditures and Recipients, 2000" published by the U.S. Department of Health and Human Services also shows that state and local governments have relied heavily on SSBG to provide critical child welfare services. However, it has also been used extensively to support elderly and disabled persons. **In fiscal year 2000, over half a billion in SSBG funds went for community-based services for the elderly and disabled.** Twelve percent of SSBG funds

($331,533,000) were used for disability services, and over $181 million for services to the elderly. These services are categorized as:

- Adult foster care
- Residential treatment
- Special services- disabled
- Transportation
- Congregate meals
- Home-delivered meals
- Adult day care
- Protective services adult

The report also demonstrates the flexible manner in which states utilize the block grant. For example, Montana used the funding almost entirely to support persons with developmental disabilities. Texas, on the other hand, used over $85 million of their grant for services to elderly persons.

The Role of SSBG Funds in Adult Protective Services

The SSBG Coalition is submitting testimony to highlight the fact that this Block Grant, Title XX of the Social Security Act, is by far the largest source of federal funding being used to address elder abuse and neglect. Unfortunately this important source of funds has been severely cut over the past five years, jeopardizing support for thousands of elderly individuals.

The latest data collected from the reports submitted by states for federal fiscal year 2000 indicates just how vital a role this block grant plays in funding state and local programs to address elder abuse and neglect. In fiscal year 2000, 32 States used over $136 million in SSBG funds for adult protective services. In funding these services a total of

approximately 667,376 adults received services that were funded in whole or in part with SSBG funds.

Surveys by United Way of America and the National Association of Counties found that diminishing SSBG funds force adult protective service agencies throughout the country to make impossible choices on who to help, and who to leave behind. Two examples from the surveys highlight this case. Cuts to SSBG forced a 50 percent decrease in the number of neglected and exploited disabled and elder adults served by the Utah State Adult Protective Services, from 158 in 1996 to just 76 in 2000. DuPage County Metropolitan Family Services of Wheaton, Illinois uses SSBG funding to support seniors who are homeless or are victims of elder abuse who are unable to stay in their homes or the homes of their caregivers. This program is the only one in the county that can provide for the unique physical and emotional needs of older individuals. Over the last five years, as need has increased, SSBG funding to the agency has remained stagnant.

The component services or activities that are funded by SSBG may include: investigation; immediate intervention; emergency medical services; emergency shelter; case plan development; initiation of legal action (if needed); counseling for the individual and the family; assessment/evaluation of family circumstances; alternative or improved living arrangements; assistance in obtaining benefits, such as Medicare, Medicaid, or private health insurance; and case management and referral to service providers.

It is important to note that the $111 million in funds spent on protective services and elder abuse through the Social Services Block Grant far exceeds the $4.73 million appropriated through Title VII (Elder Abuse) of the Older Americans Act.

Recent Congressional History of SSBG

We are here not only to highlight the significance of SSBG and its role in addressing this national challenge but we are here to highlight the fact that this vital source of funding is under severe budget pressure.

The Social Services Block Grant was enacted in 1981 when federal matching funds for social services and funding for social service staff training were combined into a block grant to states. These changes were part of the Omnibus Budget Reconciliation Act, PL 97-35 (OBRA). Before 1981 these federal matching funds covered a range of human services including programs for families on AFDC, services to keep elderly adults and children out of institutions and a range of community-based programs. The 1981 Act capped funding, increased state flexibility and converted SSBG into a mandatory fund. Funding was set at $2.4 billion in 1982. In 1985 it was increased to $2.7 billion, a level it stayed at or near for most of the next decade until 1996.

With the passage of the welfare reform act in 1996 (PL 104-193), SSBG was changed in several ways. Funding was lowered to $2.38 billion in fiscal year 1996 through 2002. In 2003, funding was to increase back to the $2.8 billion level. PL 104-193 also allowed states to transfer up to 10 percent of their Temporary Assistance for Needy Families (TANF) block grant into SSBG. The transferred funds must be spent on children or their families whose income is at or below 200 percent of the federal poverty level. It is vital that the Committee understands this provision regarding the states' ability to transfer 10 percent of their TANF block grant. Some have argued that because states have TANF funds they can transfer some of that TANF block grant into SSBG to make up for any reductions to SSBG. The law however makes clear that these funds can

only be spent on children and their families at 200 percent of poverty or below, which excludes most elderly and disabled persons.

Despite the fact that SSBG had been cut in fiscal year 1996 and had contributed significant amounts to welfare reform's budget savings, and despite the mandatory nature of SSBG funding, it became vulnerable to the annual decisions of appropriators. For fiscal year 1998 SSBG was cut to $2.299 billion. The following year SSBG funding was used as an offset in the Transportation Equity Act for the 21st Century"—the transportation reauthorization. The cuts were to be $1.9 and eventually $1.7 billion. That legislation not only reduced SSBG funding to $1.7 billion in fiscal year 2001 and beyond but states were limited in their ability to transfer TANF funds into SSBG to no more than 4.25 percent of their TANF grant.

We hope this Committee will use this opportunity to bring to the attention of those advocating for a more aggressive national strategy to address long-term care and elder abuse and to bring to the attention of all members of Congress the important role that SSBG does play in addressing these challenges. If we focus in on the elder abuse and the need to address this problem as one key elements of the long term care need in this country we see just how significant SSBG has become. By some estimates over sixty percent of funding to address elder abuse is provided by state and local governments. The reliance on over one hundred million in SSBG funds demonstrates an increasing need for further resources. Restoring funding to SSBG would be an important action towards this goal as well as a signal by Congress that they are willing to address this problem at a national level. While recognizing SSBG's role as part of that solution everyone must be warned that it's future is under great threat. We hope that the Senate Select Committee on Aging will highlight the need to restore funding to SSBG.

Some members of Congress have recognized this need and have introduced legislation that would restore SSBG to $2.38 billion this fiscal year. Senate Bill S. 501 introduced by Senator Bob Graham of Florida and cosponsored by Special Committee Chairman Breaux, Committee members Jeffords, Lincoln, Collins, Kohl, Hutchinson and Carnahan would help address some of the funding needs that the tragedy of elder abuse calls out for. However, as the 107th Congress draws to a close, there is another vehicle to restore SSBG, the Finance Committee passed Community Solutions Act (HR7). This legislation, formerly known as the Care Act would provide a two-year restoration of SSBG, a restoration that is of critical importance in this time of economic uncertainty.

We urge the Committee to continue its work in this area hope that it will recognize as part of that strategy the restoration of funding to Title XX of the Social Security Act, the Social Services Block Grant.

The Social Services Block Grant Coalition

(For further information and a list of nearly 300 national, state and local organizations that have signed onto our letter of support for SSBG please contact the chairpersons listed on the cover page)

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