HOME CARE: THE AGONY OF INDIFFERENCE
The Role of the Older Americans Act in Assuring Access to Quality Home Care

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OPENING STATEMENT BY SENATOR JOHN MELCHER, CHAIRMAN

The CHAIRMAN. The committee will come to order.

This morning we are going to have a hearing on a group of people who are, generally speaking, out of sight and out of mind. They are the people whom most of us have forgotten about, who are bound to stay at home because their health isn’t good enough for them to leave home and they require home health care. No one sees these forgotten Americans. Except for their families and an occasional visitor, they are seen by so few that they will gain more prominence after death. If they have a tombstone in a cemetery, more people will see their names in a week than people who saw them in a year during the last years of their lives.

These people who need home care and can’t leave home because of their health vary in age from young, to middle-aged, to older Americans. But of the 5 million Americans who need home health care in order to live any kind of a life at all, almost all of them are elderly.

Now, if they are shut-ins at home needing this extra care, even for those with moderate incomes, it is a tremendous cost. It is a monumental cost. This group of people really knows what catastrophic health coverage is all about. It is the most significant group that needs catastrophic coverage.
Well, what are we doing about them? What kind of attention are we paying them? Well, through Medicare for the older Americans we have a requirement in law, but Medicare has failed in its responsibility to meet those requirements.

In order to get the proper perspective, this hearing today will provide us with insight from victims, from older Americans who are victims of their health care needs because they are not getting adequate care at home.

We will also hear from the Administration. The Administration will provide some witnesses who are going to explain or excuse themselves for why the law is not being met, why it is not being carried out and why they are avoiding or failing to carry out the requirements of Medicare.

The inspector general will give us some real background information and a lot of facts that are very significant and, frankly, very disappointing. He will describe the failures of carrying out the law and the failure of Medicare requirements to meet home care.

We know what we are going to find out from the inspector general is that there are provisions under the law and under Medicare to set up the requirements and the regulations for how home health care is to be carried out. The regulations required by Congress are not really in place and therefore the law is not being met. We will find out that despite that, there is $2 billion spent on Medicare every year for health care businesses to provide the home health care required.

We will find out that the health aides that are sent out to the homes who are getting this $2 billion from Medicare are pretty proficient at bathing and combing the hair, the routine things that people have to have. But we also will find out from the inspector general, from the inspections that he has made, in 91 percent of the cases, home aides failed to record extensions of skilled services prescribed by a doctor. What does that mean? We will find out that home health aides are not very well trained in many instances, and some are incapable of reading a thermometer, measuring, checking the food intake, or checking bowel movements.

Well, this is a pretty sad series of condemnations. These failures are staggering. But what we expect out of this hearing today is to establish an adequate foundation to correct these failures to see if we cannot end some abuses.

At this point in the record, I would have placed in the record, without objection, the prepared statements of Senators Dick Shelby and Alan Simpson, along with my own prepared statement.

[The prepared statements of Senators Melcher, Shelby, and Simpson follows:]

Opening Remarks of Senator John Melcher, Chairman, Senate Special Committee on Aging

Good morning. On behalf of my colleagues, I'd like to welcome everyone to today's hearing by the Senate Special Committee on Aging.

I called today's hearing to explore one of the fastest-growing industries in the United States today—the home-care industry. It is a multi-billion-dollar, virtually unregulated industry that does pretty much as it pleases.

In this time of medical cost-containment pressure, we turn increasingly to this industry. We trust to these people our loved ones—both young and old—who only want to recover in the friendly confines of their own homes. We trust these people
to bring professional dedication and competent skills into private residences to help the sick recover.

In many cases, home care experts provide excellent and caring attention. And I applaud their professionalism. But far too often, Americans are suffering and—and in some cases—dying because of poor or fraudulent home care.

Today, we'll be hearing from several witnesses—victims and home-care providers alike—who will outline in chilling detail the shocking problems with this uncontrolled industry.

We'll also have an opportunity to examine the results of a study that shows that many home-care aides can't read a thermometer. And, I suspect, many wouldn't know the difference between a bedpan and a frying pan.

Even the Reagan administration acknowledges the far-reaching problems with the home-care industry. The Inspector General of the Department of Health and Human Services has found the quality of home-care severely lacking. And he detailed those problems in a previously unpublished, internal report that I obtained and will release today.

But although it has known about these appalling problems for years, has the Reagan administration done anything about them? The answer is no. Absolutely not! But I guess that's understandable since this isn't another defense project.

Now, I think we all agree on one thing: it's our responsibility to help the elderly and the sick. We have to offer reasonable alternatives to the high cost of hospitals and nursing homes. And that means home care. But not the kind of home care in which patients are ignored, physically abused or robbed. No, I'm talking about a type of home care that provides attentive care, nutrition, transportation, and a number of other services for those who depend on home care aides.

And I intend to find a way to rein in the industry and insure quality home care to the millions of Americans who need it.

Another problem we need to study is how to find a cost-effective way to keep people out of hospitals that cost hundreds of dollars a day and put them in their homes in the care of dedicated home-care professionals. Is it cheaper for Americans to recover in their own homes with a home-care aide? If so, can the Older Americans Act be used as a vehicle to expand both the quality and quantity of home care?

I'm looking forward to the testimony of today's witnesses. And I hope they will give us a clearer picture of the current state of home care and what can be done to give millions of Americans quality home care and peace of mind.

STATEMENT OF SENATOR RICHARD SHELBY, U.S. SENATE SPECIAL COMMITTEE ON AGING

Mr. Chairman, I am sorry that my schedule prevents me from attending the hearing this morning. I commend you Mr. Chairman, and the committee staff for organizing this hearing. As I have recently returned from my own field hearing in Birmingham, Alabama, I truly understand the great amount of work and effort that are necessary to organize an effective exchange of ideas.

We are here today to evaluate the role of the Older Americans Act in assuring access to quality home care for our nation's elderly. We will hear not only from victims, whose private stories told straight from the heart, will provide us with a glimpse of the very personal and at times shocking side of home health care; we will also hear from the Administration witnesses who will tell us what oversight currently is in place over medicare-certified home health care agencies and what quality problems they have identified with such care. Finally, we will hear from the providers, whose experience in the field will help us see the many obstacles to insuring consistent quality care.

Although my Birmingham hearing focused on the issue of Catastrophic Health Care Coverage, I was privileged to learn a great deal about home health care. I have found that like most things in life, home health care has its both good and bad sides.

Let me state from the start, that I am a very strong supporter of home care. I believe it is perhaps one of the most primary and at the same time effective health care resources we have available to us. The roots of home health care are intertwined with the growth of our country. Long before there were major medical facilities, health agencies, research centers, or government interest or involvement in health care, there were town doctors making house calls to their home bound patients.

As medical technology became more sophisticated and hospital treatment became more widely available, the idea of the visiting town doctor grew into something
much larger, more comprehensive and even more effective. 1967 marked the beginnings of hospital-based home care programs and the concept of the out-patient recuperating at home seems to have just taken off. With the passage of Medicare and Medicaid, and Titles XVIII and XIX of the Social Security Act in 1965, home health care services became ingrained in our nation's health care network.

Today we begin work which is long overdue. We are facing a potential crisis situation if we are unable to develop a system of standards and quality assurances for home health care services. Our goals are comprehensive, and yet, not unattainable.

To begin we must determine how extensive the problem is. We need to focus some attention on what problems are associated with accessibility to these services on the community level. We need to define exactly what standards of care must be met. We need to assure that the health professionals providing care follow established training guidelines before allowing their personnel out into the field. We need to determine the scope of our quality assurance system and insure that its implementation is far reaching and effective. Finally, there must be some sort of accountability for improper care.

The time for acceptance and complacency is over. We need to respond to the cries for greater control over the quality of care—for the good of our health care network and more importantly, for the good of the home health care consumer.

I know we can not expect to have all the answers instantly, but we are moving in the right direction. I feel confident that today my colleagues on the committee will address these concerns and lay the groundwork for the task that lies ahead of us.

I am pleased that the Senate Aging Committee, under the thoughtful guidance of Chairman Melcher, realizes the need to address this most pressing issue and I look forward to reviewing the testimony from this hearing.

STATEMENT

STATEMENT
OF
SENATOR ALAN SIMPSON, MEMBER, U.S. SPECIAL
COMMITTEE
ON
AGING

I thank you, Mr. Chairman, for this opportunity to provide my comments on the issue of the quality of home health care and the services provided under the Older Americans Act. It is a distinct pleasure to be a member of this Special Committee on Aging. Although I have not been as active as I would like, I have been reading, learning and pondering these important issues. I wish to share some of my observations.

Since the inception of the Older Americans Act in 1965, we have seen an unprecedented growth in the elderly population and the services that are designed to assist them. In that time period, the number of persons over the age of 65 has nearly doubled, from 18,451,000 to 29,173,000. In the same time period, amounts appropriated by Congress for the Older Americans Act has increased nearly 100 times—to $724.7 million. The programs in the Act have certainly played an important role in coordinating and providing services to our senior citizens.

One of these services, home health care, is also funded through the Medicare and Medicaid programs. These too have experienced unprecedented growth. In the last six years, our nation's commitment to Medicare home health services has tripled to over $2.5 billion. We certainly are a compassionate nation.

In spite of this growth, or perhaps because of it, the home care industry seems to be experiencing severe "growing pains". From about two thousand agencies in 1966 to possibly over ten thousand today, home health agencies are sprouting up all over the U.S. How do you assure quality in such a fast-moving industry?

There are always stories—sad, wretched, and frightening stories—about the abuses faced by some of our elderly. We have heard witnesses here today relate some of these stories. These kind of abuses should not be happening. How to prevent them is a most vital question. Maybe we can find a starting point by looking carefully at some of the institutions in which our billions of dollars have already been invested in order to assist the elderly.

The Administration on Aging has shown through its 30 years of experience that the state and local area agencies on aging are perhaps the best means to helping older persons. This has given the states a great deal of flexibility in determining the appropriate kinds of care for their own citizens. They are also reacting to the issue of quality. With their model programs and training assistance, they hope to build up a knowledge base on quality of care in order that we can better address the issue in an appropriate fashion.

HCFA too has taken steps to address the issue of quality of care. As we have heard, their certification and survey process, medical review and review of coverage compliance are designed to inquire into quality problems. Although there is certainly disappointment in finding that the training regulations mandated by the 1980
Omnibus Reconciliation Act have not been released and we are startled at the revelation by HCFA that the quality of home care services is poor, at least they do tell us of these things. We can see where the problems lie and we must then take steps to address them responsibly.

How do we assure quality in a fast growing industry? I do not know that I have the answer to that one—that is why we participate in these hearings. But I do know that we must be very careful to assess all of the facts so that we can render a well-reasoned, responsible solution. All too often we are ready to respond automatically and almost on reflex when the words "elderly" or "senior citizen" are brought to the debate. This may be a popular political theme, but it may render us a solution that is no better than the original problem.

We have much to do. Let us do it without high drama and an appeal only to emotion. I will work hard toward that end.

The CHAIRMAN. Senator Heinz?

STATEMENT BY SENATOR JOHN HEINZ

Senator Heinz. Mr. Chairman, I thank you, and I want to congratulate you for calling us here this morning to hear the testimony on an issue that touches the lives of a very large number of Americans. I am talking, of course, about the special needs of millions of ill and aged Americans and their families for health services in their homes.

Last July this committee, which I then had the privilege to chair, focused on this issue a little differently. We had a hearing in Philadelphia, where we found that backdoor budgeteering had resulted in arbitrary, confusing, and even illegal decisions to deny thousands of older Americans access to home health services under the Medicare program. We learned that since implementation of Medicare's new payment system for hospitals, the DRG's, discharges to home health care had increased by 37 percent, yet for the same period the data from the Health Care Financing Administration showed a staggering 133-percent increase in denials for home health care.

The problem then was an overzealous Administration which, armed with pruning shears, was clipping away benefits with an apparent disregard for our, Congress' intent. The problem today is an unresponsive Administration with, I fear, eyes blind to abuses and hands tied against mandated change.

Access to home health care may allow choice of independence over institutionalization for seniors who live alone. For others, lucky enough to have a family at hand, like the parents of Mrs. Grudza, one of my constituents who will testify later, these services provide breathing space. They can help lighten the tremendous financial and emotional strains of caring for loved ones.

But we might ask what good is independence when the price is neglect, indignity and pain? What load is lightened by incompetent, unreliable, dishonest, or even physically damaging care? Mrs. Grudza and our other witnesses this morning will depict all too poignantly the current gap between a good idea—home health care—and an often badly administered benefit.

Medicare's regulation of home health care providers is the bellwether for other programs, including the Older Americans Act and the Veterans' Administration. But the 2.5 million seniors who took advantage of the Medicare benefit last year did so at their own risk. The fact is we have neither standards nor surveys, and thus
no certainty that the caregivers participating in the program know a bedsore from a bunion.

We see the chart to the chairman's right, and the very first item is one that should shock everybody. The fact that some 44 percent of the home health aides surveyed could not read this thermometer, which, when the mercury goes above the little line around 98.6, is evidence of an infection. It means that many of our seniors who get help are getting it at some risk.

Back in 1980 Congress mandated that all home health aides should complete a training program to be developed by the Secretary of Health and Human Services. Here we are, it is 1987, seven years later, and we have yet to see one single graduate of this program, much less a curriculum. What we do have are reports from the Inspector General, as Chairman Melcher has indicated, from the Visiting Nurses Association and from scores of individuals nationally, of poor-quality care.

That, among other reasons, was why last week I joined with Senator Bradley of New Jersey to introduce the Medicare Home Health Care Services Improvement Act. One provision of this bill requires the Department of Health and Human Services to set minimum proficiency standards for all persons delivering home care services. We need other legislation to make the promise of quality home care a reality.

Mr. Chairman, I look forward to working with you and the other members of this committee to do just that.

Let me, if I may, Mr. Chairman, just note—and I know Senator Chafee is in the same bind—there is a meeting that Senator Packwood has called for the minority to discuss the trade bill at 10:30, so unfortunately I am going to have to absent myself. I hope it may be possible to hear from the testimony of my constituents prior to that time. But if not, I want to let Mrs. Grudzka know why I may have to leave.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Heinz.

Senator Bradley?

STATEMENT BY SENATOR BILL BRADLEY

Senator Bradley. Mr. Chairman, thank you very much. Mr. Chairman, I too want to commend you for holding this hearing. I think that it is an important health care issue, and I think that we need to closely examine the problems of home care quality and access, especially in light of the rapid expansion of home care in the last several years and the even more rapid need for home care services. We have a DRG system that continues to push people out of the hospitals of this country quicker and sicker; we need an adequate home care program to care for them in their home environment. This means that we have to face up to issues of access to home care and quality of home care.

The bill that Senator Heinz mentioned that several of us introduced last week expands the Medicare home health benefit dramatically, expanding access to 60 days of daily acute care. But it also addresses the quality problem which I think is the focus of this hearing. It addresses the quality problem in a number of ways.
First, it requires nonlicensed home health aides to complete a training program approved by the Secretary of HHS.

Second, it requires HCFA to look at patient outcomes when it monitors home health quality; in other words, how the patient has fared, not simply what the educational level is of the people who run the agency.

Third, it establishes spot checks of home health agencies, and those spot checks could lead to intermediate sanctions, civil sanctions, and indeed loss of Medicare reimbursement.

Finally, it establishes a hotline and an ombudsman to look into consumer complaints about home health care quality.

So I think that what we have tried to do is say, "Look, we want to provide home care and expand access to home care to more Americans in need, particularly those Americans who are being pushed out of hospitals quicker and sicker; but, we also have an obligation to ensure that they receive quality health care."

I think these things—the hotline, the ombudsman, the spot checks by HCFA, the civil penalties, the required training, and looking at how the patient actually fares—will take one large step toward ensuring quality for our seniors who are in need of home care but in even greater need of quality home care.

So I think we will have a continued responsibility to look at this thoroughly. This committee is the committee that should provide oversight, and I look forward to working with the chairman and other members as we try to bring to light those abuses and problems and neglected areas that sometimes crop up even given the best of intentions.

Mr. Chairman, I would like to submit some questions for the record if that would be possible.¹

The CHAIRMAN. It certainly is. Just leave them here and we will do that.

Senator Chafee?

STATEMENT BY SENATOR JOHN CHAFEE

Senator CHAFEE. Thank you, Mr. Chairman.

Like several on this committee, I am a member of the Finance Committee, where of course we have jurisdiction over Medicare and Medicaid. One of our concerns obviously is not only the availability of health care but the quality of it.

As people know, over recent years, because of the changes in the Medicare program, the discharges from the hospital are much quicker than they were in former years, and there is an incentive, in other words, to get people out of the hospital. This has created what I believe to be a critical gap in the services available to Medicare beneficiaries. They come out of the hospital, but then what happens? Individuals who receive care in their home following discharge from the hospital are vulnerable to the quality problems.

Now, the Federal Government's role is to assure that services are there, but what the Federal Government has been doing is spending more time reviewing the capacity of the home health care agencies rather than the quality of the services that are delivered.

¹ See appendix II, p. 230
So I feel strongly we have got to put much greater emphasis on providing post-hospital care in the home and on providing a wider spectrum of services and make sure that those are quality services. So thus I have joined in cosponsoring Senator Bradley’s bill S. 1076.

I also have legislation myself, S. 1010, which is called the Medicare Community Nursing and Ambulatory Care Act. Now, the purpose of that is to improve the delivery of home health care services to Medicare beneficiaries. What it would do is it would allow Medicare to reimburse community nursing centers for Medicare beneficiaries who elect to enroll in those programs. These centers would provide all ambulatory care services now offered under Part B of the Medicare program except the physician services. The services would be provided under the supervision of registered nurses, and there would be safeguards to ensure high quality.

Now, in return for providing these services, the community nursing center will receive 95 percent of the total amount we are now paying for those same services for each Medicare beneficiary. These centers would work in much the same way as the HMO, the health maintenance organizations do.

I think this, combined with the bill Senator Bradley was referring to, his bill, will help fill the gaps created by the Medicare prospective payment system.

So, Mr. Chairman, I would ask that my full statement be included in the record at this point, and I deeply regret this conflict with the longstanding Finance Committee meeting that Senator Heinz referred to.

The CHAIRMAN. It will be made a part of the record.

[The prepared statement of Senator Chafee follows:]

STATEMENT BY SENATOR JOHN H. CHAFEE

Mr. Chairman, today’s hearing will examine the quality of health care services that individuals receive in their own homes. We will hear from individuals who have experienced substantial problems with health care providers in their own homes. We will hear also from two nurses who will describe the lack of preparation given to professionals who provide home health care services. Finally, we will hear testimony from representatives of the administration and provider organizations.

As a member of the Senate Finance Committee which has jurisdiction over the Medicare and Medicaid Programs, I have become increasingly concerned about whether we are spending our Federal health care dollars effectively and whether the health care services we do provide are high quality and those most needed by the elderly and disabled.

In recent years we have made a number of major changes in the Medicare Program. One of the most far reaching changes was development of the prospective payment system which pays hospitals per episode of illness based on DRG’s—diagnostic related groups. This system, which we are still refining and improving, has removed the inflationary incentives inherent in the old, retrospective cost based reimbursement for hospital care.

However, because of the incentive built into this system to discharge Medicare patients more quickly, prospective payment has also created a critical gap in the services available to Medicare beneficiaries. When elderly beneficiaries are discharged from the hospital, services designed to help them recover and return to their previous life style are sadly lacking.

As we will see today, individuals who receive services in the home are vulnerable to quality problems, and unfortunately, the Federal Government’s role in assuring that these services are of high quality has been inadequate. The focus of federal efforts has been on monitoring the home health care agency’s capacity to provide services, rather than on the quality of those services.
For these reasons, we must put a much greater emphasis on providing post-hospital care in the home and providing a wider spectrum of long-term care services. At the same time we must assure that these services are quality services provided by trained professionals.

To achieve these goals, I have introduced S. 1010, the Medicare Community Nursing and Ambulatory Care Act and I have cosponsored S. 1076, introduced by Senator Bradley, the Medicare Home Health Services Development Act. Both of these initiatives are designed to provide better and more comprehensive home health care services.

The Community and Ambulatory Care Act of 1987, S. 1010, is legislation designed to improve the delivery of health care services to Medicare beneficiaries outside of institutional settings.

This proposal would allow Medicare to reimburse community nursing centers for Medicare beneficiaries who elect to enroll in their programs. These centers would provide all ambulatory care services now offered under part B of the Medicare Program—except physician services. The services would be provided under the supervision of registered nurses, and safeguards to ensure a high quality of care would be provided through the existing peer review organizations.

In return for providing these services, the community nursing center will receive 95 percent of the total amount we are now paying for these same services per Medicare beneficiary. These centers will work in much the same way as an health maintenance organization—an HMO.

The Community Nursing and Ambulatory Care Act will help fill the gaps created by the Medicare prospective payment system by providing a pre-determined payment to community nursing organizations designed to provide the services Medicare beneficiaries need to fully recover. Community nursing organizations will also help more Medicare beneficiaries live independently longer by providing in-home assistance to help prevent institutionalization.

The Medicare Home Health Services Improvement Act, S. 1076, attempts to ensure the availability of high quality home health services to elderly and disabled individuals in two ways. First, the bill prevents the health care financing administration from arbitrarily restricting home care services financed by Medicare by clarifying and expanding the Medicare home health benefit. Second, the bill promotes the health and safety of those receiving home care services by upgrading home health quality standards and accountability.

These two legislative proposals are a beginning, but we still have a long way to go in assuring better, more appropriate health care services for the elderly. The witnesses at today's hearing can bring us a great deal of information on how in-home services can be better monitored and have a higher quality of care.

I look forward to hearing today's testimony.

The CHAIRMAN. Senator Reid?

STATEMENT BY SENATOR HARRY REID

Senator Reid. Thank you, Mr. Chairman, for providing the members of this committee an opportunity to assess the need for development of quality assurance standards for home health care services.

I would also like to extend my appreciation to our distinguished witnesses who volunteered their time so that we may look critically at this issue of increasing importance to our Nation's elderly.

I firmly believe that the availability and quality of home health care services represent problems that require immediate attention. New technologies and the tremendous strides made by our Nation's medical professions have boosted the average life expectancy to 74.6 years of age, its highest level ever. The result is a rapidly expanding population of senior citizens, especially the group over 85 years of age. As the primary consumers of home care, these citizens require an increasing number of services provided by qualified individuals that the industry is failing to provide.

This state of affairs has been aggravated in recent years by cuts in Medicare and the institution of the DRG system, both of which
have resulted in patients being discharged from hospitals, as we have already heard, quicker and sicker and in need of comprehensive home health care services for longer periods of time.

During the time that I served as a Member of the House, I was on the Select Committee on Aging. The committee conducted one hearing that made me acutely aware of the lack of data on home health care quality and the inadequacy of the current system of standards and quality assurance. Agencies that provide home health care services are experiencing diminished resources from public sources, including Medicare and Medicaid, which has contributed to the hiring of underqualified personnel—as was very well described by Senator Heinz—who will accept lower wages and irregular work schedules.

Although this problem is not characteristic of all agencies, consumers of home health care services are seldom in a position to choose knowledgeably among home care providers, and no easily usable grievance procedures are available. Moreover, because these services are rendered in private residences, many times the quality of home care is difficult to measure. Those systems for monitoring home care that do exist contain few sanctions for inadequate care and few, if any, incentives for outstanding care. Legislation is badly needed now to require the development of stronger, uniform standards of home care, the monitoring of service delivery, the establishment of a grievance mechanism, and enforcement.

It is also of primary importance that additional cuts in funding of such services be prevented. I am hopeful that today's hearing will raise new questions and bring to light additional information that will help us formulate responsible policy to serve the home care needs of older Americans.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Glenn?

STATEMENT BY SENATOR JOHN GLENN

Senator Glenn. Thank you, Mr. Chairman.

I don't think anyone doubts we need a national commitment to provide home health care to those who need help—help to which they are entitled, and of the highest quality. We tend to think of aid to the elderly, help to the elderly, nursing needs as being something that is the province of nursing homes or hospitals. And yet statistics tell us that 80 percent of the health care needs of the elderly are met by family members. In other words, most of our elderly people are being taken care of in homes.

Now, that being the case, we are not giving the kind of help to that home health care that we should. I don't think there are too many of us on this committee that has long been involved in home care, under Senator Heinz and Senator Melcher both, who would disagree with that. We need to give much more support for home care services, because that is where most of the help can be given, and it could be given cheaper there. We can save money doing it that way. We don't need to warehouse people in order to give them help.

We should be expanding our support in this area, not lessening it. Yet, as we see this additional need, we have seen less support
out of this Administration to giving that kind of help. I find that unconscionable. By restricting access to Medicare's home health benefit, we increase the burden on other programs such as Medicaid, the social services block grant, Older Americans Act, Veterans' Administration, State programs, private insurance, and patients. We leave the patients too often without needed home health care.

That is what this is all about this morning. I am sure we will hear horror stories this morning that will make us cringe because we haven't done enough in the past here. We have heard some of those before. These are the real people. These aren't academic problems we dream up with staff here in Washington and decide some big national solution inside the Beltway here in Washington. These are real stories of hurt. So we need to do something in this area.

I am proud to have joined Senator Bradley as a cosponsor of the Medicare Home Health Care Services Improvement Act of 1987, and I am pleased to be a sponsor of the legislation being considered as part of this year's reauthorization of the Older Americans Act which provides grants to State nursing home ombudsmen to demonstrate and evaluate the provision of ombudsman services to home care clients. It requires a study of the State ombudsman programs also, particularly in the area of home care services and how those are being rendered or not rendered.

Let me add this, too, before we get too critical. The majority of home health care providers are honest and they are doing their very best, quite often with very, very limited resources. I have been in I don't know how many nursing homes. My wife Annie was asked some years ago back home in Ohio to be the head of Nursing Home Week, be the honorary chairman of Nursing Home Week. She made visits to many nursing homes all over the State, actually checked into some of those homes and stayed overnight so she could see what it was really like.

Out of that came our interest in this and our dedication to doing something about it. That was the main reason why I asked to go on this committee. I wasn't assigned to this committee. I asked to go on it when I got here.

So we need to realize that most nursing home and home health providers are honest and dedicated people. They are doing excellent work, but too often they don't have the wherewithal to do it. They don't have the support of their Government or of enough local agencies to really accomplish what has to be done. So we need very much to improve this.

It is a pleasure for me today to welcome one of our witnesses, Ann Mootz, who is here from Ohio, from Cincinnati. She is representing the National Association for Home Care, and I look forward to hearing her testimony later. As with all of us, we have too many things to do this morning and I have to be away from the hearing for awhile. I hope to get back a little bit later, particularly when Ms. Mootz is testifying.

Home health is an area we have let go too long, Mr. Chairman. I would ask that my entire statement be included in the record.

The CHAIRMAN. It will be made part of the record.

[The prepared statement of Senator Glenn follows:]
Mr. Chairman, we need a national commitment to provide elderly and disabled Americans with the home health care they need and to which they are entitled—and to ensure that this care is of the highest quality. Improving the provision of home- and community-based services has been a priority issue of the Senate Special Committee on Aging for many years, and I commend you for calling today's hearing.

Home care services are very important in meeting the health-care needs of the sick and the disabled; and this need is increasing due to our growing "old-old" population, "quicker and sicker" discharges of Medicare patients from hospitals, technological advances in health care delivery, and a preference for home care over institutional care. But at a time when the demand for home health care is increasing, the Reagan Administration's policies are severely restricting access to Medicare's home health benefit, thus increasing the burden on other funding sources for home care—Medicaid, the Social Services Block Grant, the Older Americans Act, the Veterans' Administration, State programs, private insurance, and patients and their families—and leaving patients without needed care.

In addition to the problem of access to home health services, we have all read and heard horror stories about poor care and abuse of the elderly in their homes. Today we will hear dramatic accounts from patients, their families and providers about tragedies that occur due to lack of training, supervision and standards for home health care.

In order to address these issues, I was pleased to join Senator Bradley as a cosponsor of the "Medicare Home Health Services Improvement Act of 1987". Enactment of this legislation will go a long way toward ensuring the availability and improving the quality of home health services provided under the Medicare program.

And I am pleased to be the sponsor of legislation, being considered as part of this year's reauthorization of the Older Americans Act, that provides grants to State nursing home ombudsman agencies to demonstrate and evaluate the provision of ombudsman services to home care clients, and requires a study of current State ombudsman programs which are already investigating complaints concerning home care services.

The majority of home health care providers are honest and do provide excellent care. They are as concerned as we in the Congress about the need to improve the quality of care and to eliminate any abuses. Therefore, it is a dual pleasure for me to welcome one of today's witnesses, Ann Mootz—because she is from Cincinnati, Ohio, and because she is representing the National Association for Home Care (NAHC). I look forward to NAHC's recommendation for improving access and quality in home care, as well as to the testimony of all of today's witnesses. Your participation will help in our efforts to enact legislation to remedy problems regarding home health care access and quality.

The CHAIRMAN. Senator Durenberger?

STATEMENT BY SENATOR DAVE DURENBERGER

Senator DURENBERGER. Thank you, Mr. Chairman.

I am not going to victimize Ms. Tolbert and Sharon with a long speech, and I am going to stay here and I am going to listen to you.

I am glad John did make the comment about the fact that a lot of caregivers in America are, besides being very capable, are also very compassionate and that on a number of occasions we find the unscrupulous coming into any opportunity that we can find in the system.

Those of us on the Finance Committee who have tried to deal with the revisions in Medicare and the social services block grant cutbacks are extremely sensitive to the fact that as you cut back on adequate finances, you put a strain on the most compassionate people out there. I think that is one of the difficulties that this committee is going to find in the system. It isn't a lack of being well-intentioned, it's the fact that if you don't put some resources behind the best of people, they get out of the business or they scrimp on the care or something like that.
So with that I will yield whatever time I might have had for an opening statement, and I thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

Will Mrs. Grudza approach the witness table at this time?

Senator Heinz?

Senator Heinz. Mr. Chairman, in case Mrs. Grudza is wondering why she has been called to the witness table, it is simply because, as I said to Senator Melcher, I am going to have to absent myself for what I hope to be a brief time but I do not know, and I just wanted to introduce you to my colleagues.

May I say that I am delighted that you are here.

Mrs. Grudza, Mr. Chairman, is of course from my home State of Pennsylvania, and she has come to tell us about the many problems she has had with aides assisting in caring for her parents.

I want to personally thank you, Mrs. Grudza, for coming down here today. As I say, I hope I get back in time to hear your testimony. But in case I don’t, I just wanted you to know why I have to step out at least for a while. I wish you luck, if I am not here. But the chairman is both kind and compassionate and understanding, as well as being a good chairman. [Laughter.]

We are delighted you are here.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

You may stay right there, Mrs. Grudza. That would be fine.

Our first witness is Mrs. Pearl Tolbert, and Mrs. Tolbert is going to tell us what her circumstances are.

Mrs. Tolbert, I hope we haven’t created any mystification on what we are all about here today. I don’t think we have. I think our central theme is our mission today in this hearing is to hear from folks like you who are incapacitated, need some help but you are still at home. We want to know how it is with you. We want to know what has gone wrong and what the shortcomings are. We would like to do a little bit better than we have by you, Mrs. Tolbert, and we are all here today to learn and to learn from where it is really at, with folks like you.

Please proceed, Mrs. Tolbert.

STATEMENT OF PEARL TOLBERT, RESIDENT, STATE OF MINNESOTA, ACCOMPANIED BY DR. SHARON GLOVER, DAUGHTER

Mrs. Tolbert. Well, one of the million things I had to happen to me was I have an open trach, and whenever I am given a bath, it is to be covered with tape. My attendants know this. I had an attendant put me in the shower and drew the water, and the hole got water in there, and we had to call 911 because I was strangling.

Then I had an attendant who put me in the shower, pulled off his clothes and got in the shower also.

I had an attendant take my credit card and buy a thousand-dollar couch set, and then when the bill came in to me and I confronted her with it, she said, “Oh, well. I’ll pay it.” She didn’t pay it, and it ended up that I had to go to Sears’ and they had to get the police in on it.

Then I had an attendant who got in the bed with me and had sex, and I went through it.
Then I have had attendants steal my clothes and steal my pots and pans. And it's just rough getting an attendant.

I think what happened, there is a place we call, and they send them out. They just send anyone who applies instead of trying to screen them and find out some of their characters, you know.

I also had two workers. A girl worked the evening and a boy that worked lawns, and they started to going together, and then this boy went home with her one night, and it looked like she was going with the fellow upstairs, and he killed him.

You know, it's been one thing after another.

The CHAIRMAN. Mrs. Tolbert, you live in Minneapolis; is that correct?

Mrs. Tolbert. Yes.

The CHAIRMAN. Where is your home in Minneapolis?

Mrs. Tolbert. Nicklett Street. It's downtown.

The CHAIRMAN. It's downtown. And are you in an apartment?

Mrs. Tolbert. Yes, I'm in an apartment.

The CHAIRMAN. How long have you been in a wheelchair?

Mrs. Tolbert. Oh, I've been in a wheelchair since 1980.

The CHAIRMAN. You've been in a wheelchair about 7 years then?

Mrs. Tolbert. Yes. I can't use my hands and I can't, you know, walk. I walk just a little with a walker.

The CHAIRMAN. With the walker.

Mrs. Tolbert. I can walk a short distance with it.

The CHAIRMAN. You can walk a short distance with a walker.

Mrs. Tolbert. Yes.

The CHAIRMAN. And that is only in your home?

Mrs. Tolbert. Yes. Only in my home. I can't use my hands. I can't even go to the bathroom by myself.

The CHAIRMAN. Now, Mrs. Tolbert, would you mind telling us how old you are?

Mrs. Tolbert. I'm 70 years old.

The CHAIRMAN. Seventy.

Mrs. Tolbert. Yes. I was born in 1916.

The CHAIRMAN. And you have been incapacitated for the last 7 years.

Now, this is your daughter, Dr. Glover, seated beside you?

Mrs. Tolbert. Yes.

The CHAIRMAN. Dr. Glover, can you add anything to your mother's testimony that would help this committee?

Ms. Glover. Yes, I can.

The CHAIRMAN. Would you draw the microphone closer to you?

Ms. Glover. I routinely spend about 30 hours a week minimum trying to supervise the attendants because of the situations that we have had. We have had just many attendants, and I can say that consistently I see the same thing: a lack of training, a lack of willingness on their part, and that additionally, even with these problems, there isn't very much that you can do.

The demand for attendants is so great that you can fire them, and 30 minutes later they have another job. In fact, my mother's nurse, the State nurse that comes to see her weekly, came to see her, and there was an attendant abusing her badly, and the nurse
fired the attendant on the spot. Within an hour that attendant had another job.

We have tried with all of these situations to find someone that we could talk to, someone that we could tell what was happening. And it's almost like an impossible situation. The agency that we get the attendants from has not been helpful at all. Our only other choice is to go to the newspaper, put an ad in the paper, place ads in the paper, read the paper, try to call other agencies.

One other agency that we have been somewhat successful in getting people from is church center. Now, they aren't an agency, but from time to time people will call and say that they are interested in doing this kind of work. But we have found just consistently what you have on that board is absolutely true.

I really feel sorry for someone who is in this situation and who doesn't have someone such as myself to advocate for them and to spend some time, because I find that if you don't, then they abuse them even worse, even to the point of striking these people.

The CHAIRMAN. Dr. Glover, your mother practically lives in downtown Minneapolis. Where do you live?

Ms. GLOVER. I live in Golden Valley. I live approximately 7 to 8 minutes from my mother.

The CHAIRMAN. Seven to eight minutes.

Ms. GLOVER. Seven to eight minutes. And I am at her house approximately 3 to 4 evenings a week and once on the weekend, and I drop in at different times to be sure of her situation. I find that is the only way you can stay on top of it.

The CHAIRMAN. Dr. Glover, what is your profession?

Ms. GLOVER. I suppose I am an educator.

The CHAIRMAN. You are an educator. Have these circumstances prevailed for the 7 years that your mother has been incapacitated at home? Have all of those 7 years been about the same. Is the situation bad to begin with and still bad, or has it gotten worse?

Ms. GLOVER. My mother has been incapacitated at home for 5 years.

The CHAIRMAN. Five years.

Ms. GLOVER. Of those 7 years, she spent 2 years in the hospital. The CHAIRMAN. I see.

Ms. GLOVER. Totally paralyzed. Then she has been home 5. And, yes, I would say from day one it has been the same.

The CHAIRMAN. Been the same. No improvement?

Ms. GLOVER. No improvement. In fact, I think maybe it's worse. I have noticed that the caliber of people that we are getting, that it's worse. I have noticed that the selection is worse. We have, for instance, an attendant right now who can't read or write. It means that if I call about a medicine prescription or something like that, I had better be prepared to go over there myself and get the information. It means that that attendant can't give medicine and other kinds of things, and so someone such as myself or a nurse will have to go in at the beginning of the week and lay out these things.

The CHAIRMAN. Senator Reid?

Senator Reid. Do you think—and, Mr. Chairman, I am asking this question because I don't know—do you think one of the reasons that the problems could be worse is because there is a greater
demand for home health care than there was, and there are fewer people to go around?

Ms. Glover. I don't know. But what I do know is that the quality of the people I am seeing in home health care and their training, et cetera, is not what it should be. The lack of training—people are hired and sent out on a job without any training whatsoever.

Senator Reid. Mr. Chairman, it is not only in this area that problems have developed but in other areas as well, such as the break-up of the telephone system. It has become so expensive for people to have a telephone and it is impacting on older people more than on any other sector of our population. In consideration of this situation and problems associated with home health care, for someone who doesn't have a child—and principally it's a child who looks out for the parents—the problems are really almost insurmountable.

What would your mother do but for you? I mean, who would help? The answer is obvious: there is no one, is there?

Ms. Glover. I don't know. You know, you mentioned telephone. We have had incidents where she has tried to call me because she was being abused, and the attendant has ripped the telephone out of her hands and refused to let her call me, put her against the wall like she was a 3-year-old, put her in the corner.

The question, what would she do? I don't know. I really don't.

Senator Reid. You see, Mr. Chairman, we are fortunate to have a witness like Pearl Tolbert come before us. I think she is an example to us of the multitude of people that are not before us. Her situation is very bleak, but consider the fact that she has a bright, educated daughter to help her, and we have so many people who have no children, no family, no friends to help them. They aren't before us, and we can imagine what those situations must be.

I have no further questions.

The Chairman. Thank you, Senator.

Senator Durenberger?

Senator Durenberger. Thank you, Mr. Chairman.

I don't know where to begin. If Sharon is 7 minutes away, I am about 30 seconds away, Pearl, and I want to give you my telephone number on weekends so you can call me.

I know there are a lot of people in home care and home health back in Minnesota who, when they see this, are going to be cringing, because this is a very untypical Minnesota situation in terms of the impression that the rest of the country has.

So I have to believe that to the degree that in a State like ours, which is as sensitive as it is, Mrs. Tolbert, that you are having to live these years with that kind of condition makes it a very, very serious problem for a whole lot of people who aren't able to come here and testify today.

But perhaps, Mrs. Tolbert, you won't mind if I ask Sharon a couple of questions about the State in which we live and the community in which we live and the way in which they have been responsive to these same kinds of concerns.

Obviously, if the kind of behavior on the part of attendants has been going on for some period of time, which I assume it has, that officials in the City of Minneapolis, the County of Hennepin, and in the State of Minnesota, which has a relatively sophisticated, through the Department of Health, procedure—or thinks that they
have a procedure at least—for ensuring the adequacy of professional care in some of these areas, should have taken some action. I wonder if you wouldn't, Sharon, describe for us the efforts that you have made at the local and the State level and what kinds of response are you getting from people back there?

Ms. GLOVER. When we have had problems, we have turned to a State nurse, we have turned to Independent Crossroads, which formerly was the Comprehensive Services, we have turned to Human Resources, the Medicare unit. No one either seems to be or wants to be responsible. We are continually told that there is nothing anyone can do.

When things have been stolen from her, when people have threatened to hit her, when they have put her up against the wall, we have been told by Independent Crossroads that they are only a hiring service. The nurse has helped all she can. I mean, she will try to get us other people. We just don't—we don't know where else to turn.

What we have done, though, is I wanted to see if this was just peculiar to my mother or was this a larger problem. I have talked with a number of other people such as my mother, and we find that it is a pervasive problem. It is not just what has happened to her.

So I could tell you and give you the names of at least five other people who, just like her, the same thing has happened, and some of these people don't have anyone.

We finally reached the point of asking my husband to do something about it, and I can tell you, because of my frustration and my mother's frustration and these other people's and our trying to turn and get help but not being given help, that we asked him if he could not begin to talk to some of the political people and do something about it. And I think he has made a couple of contacts and there has been some talk there, and that's where we are with it.

Senator DURENBERGER. Now, as far as the financial assistance in purchasing attendant services, is it in part your mother's own resources, in part medical assistance, in part Medicare? Can you recall for us? What I am trying to get at is who really should be responsible? Are there so many people in the act that nobody wants to take responsibility?

Ms. GLOVER. The State of Minnesota pays for 6½—i'ts either 6¼ or 6½ hours a day of attendant care, and they pay $6.08.

Senator DURENBERGER. They pay what?

Ms. GLOVER. $6.08 an hour.

Senator DURENBERGER. Per hour?

Ms. GLOVER. Per hour. What that means is that if you have someone such as my mother who needs 24-hour care because she can't cook, she can't go to the bathroom, she can't do anything, she has no use of her hands, she can't, even if someone rings the doorbell, she can't buzz the doorbell to let them in. And additionally, because she has an open hole or the trach, she has breathing difficulties and often must be rushed to the hospital and must have someone to assist her if that happens. She needs 24-hour care.

If the State pays for 6½ hours at $6.08, it means a couple of things. One is, you are getting people who can't compete in an open market, because nobody is going to work for $36 and some change a
day. In her situation, you can’t get anyone to work around the clock, because that’s what it amounts to, and if you break the shifts in half, you’re talking about, let’s say you bring two people on, you’re talking about $15, $18 a day.

So what we do is we supplement. Now, most of the people that I know may not need as much care, but they certainly need more than 6 hours a day. What happens then is that you have people who, I believe, on an open market could not compete, and therefore they become attendants.

Senator Durenberger. Why is the State restricted to 6½ hours? Have you been through that with the State?

Ms. Glover. I have been through that. I am working on that right now with the Minnesota home health care advocacy program to see if we can’t increase the attendant hours. The State, case by case, makes a decision about increasing. It has in some—I think there are three or four people who have more than the 6½ hours. It is currently reviewing this policy, and I understand that as of July will come out with a new policy that will be somewhat more flexible to allow for situations like this.

Senator Durenberger. Now talk to me about your mother’s doctor, or maybe your mother wants to talk about the doctor. I assume she has a physician who has been taking care of her for some time and who is providing advice to the State of Minnesota or to other people relative to your mother’s needs. Can you describe that for us?

Ms. Glover. Yes. She has a doctor at Abbott Northwestern, and she goes there regularly. That was the last hospital she was in. It was the hospital that taught her to stand and to talk and whatever again, the rehab. The doctor has just given us a 24-hour care plan, has written letters to Human Resources asking them also to increase the hours because she can’t be left alone.

In fact, Abbott Northwestern has become involved with me with this attendants program because they too have recognized the problem, the continual problems not only with my mother but with other people. It was Abbott Northwestern that put me in touch with the Minnesota home health care advocacy program led by Susan Margolis, and we have been working with them, and the hospital has been working with us too to get this taken care of.

Senator Durenberger. My impression is that even if for your mother’s circumstance the State were to acknowledge that the medical advice is that your mother ought to have 24 hours of attendant care, your concern is that there aren’t adequate attendants in the State of Minnesota to provide this care because the State doesn’t supervise in any way the quality of the services.

Ms. Glover. No. My concern is about three-fold. It is that there aren’t enough attendants, that there aren’t quality attendants, and that it is an industry that is not regulated and anything can go on in that industry.

We supplement, or we pay the people now, but that doesn’t matter. If something happens, there is nowhere to turn to because it is an industry that they can do anything that they want because the demand is so high and there is no one that you can turn to.

When they stole my mother’s—my brother gave her a gold piece from Africa—when they stole that, there was nothing we could do.
And not only did we know who had taken it, one of her attendants, the one that killed another man, took it, gave it to this girl, the girl called and said she had it and, "It was too bad."

You call the police, and there is nothing they can do. You call Independent Crossroads, there is nothing they can do.

I mean, that doesn't even begin to get it. I have been at her house where an attendant has said, "I ought to slap you." I mean, the kind of abuse I have seen is just ridiculous. And if I have seen it, and I have put the kinds of time I do in, I just feel sorry for other people.

Senator Durenberger. Thank you.

The Chairman. Dr. Glover, in other words, the quality of the attendants who come and who are paid to come is not very adequately checked. You had somebody, one of the aides who actually stole from your mother. Your mother has mentioned the aides' lack of training when she was put in the shower with her trachea tube out?

Ms. Glover. Pardon me?

The Chairman. Did I understand your mother correctly, she was actually put in the shower—

Mrs. Tolbert. They have to put tape on it so that no water gets in it.

The Chairman. Her trachea open, without being closed, I guess she could have drowned? Is that it?

Mrs. Tolbert. Yes.

The Chairman. In other words, regardless of who pays for it, you can't find somebody who is adequately trained. Have you talked to Medicare about this?

Ms. Glover. No. I haven't talked to Medicare. I talked to the agency, the one agency we have in Minnesota—and we only have one, Independent Crossroads—I have talked to them about it. I go in and try to train the attendants myself because there is no one else to train them. The agency does not train them.

The Chairman. The agency does not train them?

Ms. Glover. Does not train them.

The Chairman. All right. Well, thank you very much, Mrs. Tolbert, and Dr. Glover, for coming here today and providing us with these stark, sad facts. Thank you very much.

STATEMENT OF MARY SUMMERS, RESIDENT OF NORTHERN VIRGINIA

The Chairman. Mary Summers is our next witness.

Mrs. Summers, will you take a seat right there in the middle. We understand you are from northern Virginia, not too far away from here, part of the metropolitan area, northern Virginia.

Mrs. Summers. That's correct.

The Chairman. We understand that your husband has Lou Gehrig's disease?

Mrs. Summers. That is correct.

The Chairman. And requires constant attention at home.

Mrs. Summers. That is correct.

The Chairman. Will you tell us about it?
Mrs. Summers. All right. A comment that Senator Glenn made really hit home with me when he commented on the home care supposedly being cheaper. This has not been my experience at all. I brought my husband home from the hospital 2 years ago after spending 6 weeks in the intensive-care unit. He has Lou Gehrig’s disease. He has no use of his arms, very minimal use of his legs. He is fed with a feeding tube directly into his stomach. He is on a respirator which breathes for him.

I brought him home, and I was provided with home health care. At first, they told me they would charge $13.95 an hour. When they found out that my insurance would pay the bill—we are very fortunate to have excellent insurance that has the catastrophic clause—they upped the price to $45 an hour. And my insurance company paid them $100,000, until I finally dismissed them a year later.

The Chairman. How long has your husband been in this condition, Mrs. Summers?

Mrs. Summers. It will be 2 years—well, it is 2 years, 2 years April 6.

The Chairman. Two years this month.

Mrs. Summers. Yes.

The Chairman. Now what care is your husband getting?

Mrs. Summers. All right. This $100,000, I should elaborate on that. I use nurses only when I am teaching school. I do all the rest of his care myself. So this was just for those hours.

What I did when I dismissed the first agency, I tried another agency, and as you heard from the previous testimony, I have been very disillusioned with the kind of care that he had: a lot of incompetency. A lot of nurses were sent to our home who really did not know how to handle a respirator patient. They were not skilled in suctioning, which he needs several times a day in order to keep his lungs clear. I had malfunction of the respirator from nurses opening it to check it and obviously didn’t know what they were doing. And the respirator malfunctioned several times.

Eventually, what I did was I dismissed all agencies and I have hired nurses privately.

The Chairman. All right. Now, you mention agencies.

Mrs. Summers. Yes.

The Chairman. Now, how do you get the names of agencies?

Mrs. Summers. They solicited me in the hospital.

The Chairman. They solicited you?

Mrs. Summers. Yes.

The Chairman. And they said they could provide the necessary skilled nursing care?

Mrs. Summers. Yes. Representing themselves as being able to provide the kind of nursing care that we needed. And it was quickly obvious that they did not have nurses to fill this kind of a requirement that he needs. He needs highly skilled care.

The Chairman. You are a teacher.

Mrs. Summers. Yes, I am.

The Chairman. Is that in elementary or secondary?

Mrs. Summers. I teach middle school, sixth, seventh, and eighth grades.

The Chairman. So you are gone from home during the day?
Mrs. Summers. I leave the house at 7:30 in the morning and I am usually home between 4 and 5 in the afternoon.

The Chairman. That is 5 days a week or whenever school is in session?

Mrs. Summers. Five days a week when school is in session, yes. I try to complete everything in school before I come home because when I come home I am a nurse the rest of the time.

The Chairman. Well, how long did it take you to decide that you were going to hire the nurses yourselves, a year or 6 months?

Mrs. Summers. All right. When I first got the first bill and found that the price had been raised to $45 an hour, I called and registered a complaint. Their comment to me was, "Why are you so huffy? Insurance is willing to pay it." I said, "Well, that is not really the question." I said, "Ultimately, we are all paying for that sort of thing."

But I was quite busy at that time. I was either teaching school or taking care of my husband, and I really didn’t have time to check this out to see if they really were right. They kept telling me that this was a reasonable rate.

Then, a year to the day from the time my husband came home from the hospital, I was involved in a serious automobile accident and I was brought up here to the shock trauma center. I had to have extra nursing care for a while, and they had the audacity to charge me overtime on top of the $45 an hour that they were collecting from the insurance company.

For the first time, I had time to—I couldn’t do anything with regard to care of my husband for a few weeks, so I had time to do some checking into it. I called other agencies. I called the Muscular Dystrophy Association that funds some of the ALS patients and found that it was an unreasonable price. And that is when I made my changes.

The Chairman. Now, do you have any difficulty since you are hiring the nurses yourself personally? Do you have any difficulty?

Mrs. Summers. It’s been tough, yes, but I have three fine ones now. It took a while.

The Chairman. Then you have worked it out?

Mrs. Summers. I have worked it out, yes.

The Chairman. Would you mind telling us what that costs?

Mrs. Summers. I am paying them $20 an hour, which is more than they would make some place else, but they have to do their own billing, their own insurance and—

The Chairman. How much?

Mrs. Summers. $20 an hour, which is saving my insurance company $25 an hour.

The Chairman. Now, during the period since you made that decision, is your insurance going to keep on paying?

Mrs. Summers. Yes. I was concerned about that, and I called them. They said, yes, that they would continue to pay it. With the catastrophic clause, I have to pay the first $1,000 each year, and they very graciously pick up the rest of it. I am very fortunate, really, compared to a lot of people.

The Chairman. Yes, you are.

Mrs. Summers. Yes.

The Chairman. That is a very fine policy.
Mrs. Summers. I have tried very hard not to abuse it. As I say, I
do all of his care myself except for when I am actually teaching.
Our medical bills, total medical bills, the first year were, I think it
was, about $125,000. This year I have got it down to about $83,000.
The Chairman. That is a pretty good record.
Senator Reid?
Senator Reid. Mr. Chairman, here we have a different situation.
We were talking previously about attendants whom you would
expect to have some training. But here we are talking about regis-
tered nurses who—
Mrs. Summers. That’s correct.
Senator Reid [continuing]. Simply didn’t do what they were sup-
posed to do. You had to get rid of them because they were incompete-
tent. They couldn’t do some of the basic things that your husband
needed. I think this is really a sad commentary.
Mrs. Summers. Yes. It’s been a very educational experience for
me. I came home from the hospital naive enough to think that he
would have good care.
Senator Reid. One of them, for example—Mr. Chairman, I think
the record should make clear—ruined a very expensive respirator
that was required to keep your husband alive; is that right?
Mrs. Summers. That’s correct. This particular agency felt that it
was part of their duty to check the respirator each time they came
on shift, and the respirator that he uses is a small thing about the
sizes of a tool box and it’s in the sealed container, and it’s not
meant to be opened and shut. I tried to explain this to them, and
the respiratory therapy department that handles my husband’s
case also were upset about this being opened and shut on each
shift.
I came out of the shower one night and the alarm was going off.
Luckily, it hadn’t gone off until just as I got out of the shower, or
he would have been dead until I came out of the shower. I was able
to find what was loose.
Then, the second time, in the morning the respirator failed, I
think it was three or four times, and I found that the problem was
related to the opening and closing of the lid, which is what they
had been doing that I asked them not to do. So the respirator had
to be replaced.
Senator Reid. Also, I think it’s important here that we recognize
that you have attempted to get help from outside agencies, and this
has not been a successful journey for you either, has it?
Mrs. Summers. No. No. I got the feeling that the main thing they
were interested in was sending somebody to my house. It didn’t
make any difference if they had the necessary skills or not. I sugges-
ted in-service training for the nurses who were coming, and got
no response to that.
Senator Reid. Mr. Chairman, I have no further questions other
than to comment that the more we hear about this, the more com-
plicated it becomes and the more distressing it becomes. First we
heard about problems with attendants, and now we are hearing
about problems with nurses.
Add to that the fact that we have all these outside agencies that
are also failing to provide good quality help. That brings us back
here, Mr. Chairman, with a woman who is educated, who under-
stands what the world is all about, and still she can’t find home care service providers with which she is satisfied. And, you know, these illnesses don’t strike only husbands and wives with educated spouses.

Mrs. Summers. That’s right. That’s correct.

Senator Reid. And I can’t imagine what the other case might be. Probably the person is dead; that’s one reason we don’t have them here with us today. If we didn’t have somebody like you helping your husband, it would appear to me from the limited testimony we have heard, that he would have expired.

Mrs. Summers. That’s correct. That’s correct.

The Chairman. Thank you, Senator.

Well, I think there is one thing, though, that the witnesses have in common, and that is that an agency is supposed, but doesn’t, send a qualified person. In Mrs. Tolbert’s case, all the agency had to do was send somebody just to help with the routine things at home. They just had to know how to care for an incapacitated person who has very little use of her arms and very little use of her legs, in fact, almost paralyzed. And now in Mrs. Summers’ case, an agency sends not just registered nurses but somebody presumably who knows how to run the equipment that is necessary for Mr. Summers.

Mrs. Summers. I came home one night, and the nurse that was there that day told me, “I was scared to death when I had to suction him.” Well, that gives you a real feeling of confidence, doesn’t it?

The Chairman. Yes, it does. [Laughter.]

You know, I think what we are basically getting at, is finding out if anybody is in charge of screening people who come in and take over somebody’s life. We feel that there should be. I think all of us as citizens feel there should be. But I can assure you that those of us on this committee know that there should be.

Mrs. Summers. Right.

The Chairman. And we are going to hear from the Administration witnesses on why there isn’t some means of establishing the guidelines, and requirements that must be met before an agency sends somebody into a home? In your case, you’re not using Medicare.

Mrs. Summers. No, sir.

The Chairman. In your case it’s the insurance company.

Mrs. Summers. Yes, sir.

The Chairman. But, you know, the insurance company looks to Government just like the rest of us do——

Mrs. Summers. That’s right.

The Chairman [continuing]. And says, “Who is the referee?” And we are going to find out who the referee is and why the referee isn’t there to establish regulations for sending aides out to help somebody who is helpless.

Mrs. Summers. I called the insurance company over the exces- sive price to tell them what had happened, and they thanked me very much and said, “If more people would be like you, we could control this situation.”
The CHAIRMAN. All right. Well, you are helping. You are helping very much, Mrs. Summers. Thank you very much for excellent testimony.

Mrs. Summers. Thank you. I appreciate your concern.

The CHAIRMAN. Thank you.

STATEMENT OF NILDA GRUDZA, RESIDENT OF THE STATE OF PENNSYLVANIA

The CHAIRMAN. Our third witness is Mrs. Grudza.

You may sit right there, Mrs. Grudza. You have already been introduced to the committee by Senator Heinz. He said you are from Pennsylvania. I don't know whether he mentioned Philadelphia or not, but you are from Philadelphia, are you not?

Mrs. Grudza. Yes.

The CHAIRMAN. Will you tell us your circumstances?

Mrs. Grudza. OK.

The CHAIRMAN. And would you get close to that microphone so everyone can hear you?

Mrs. Grudza. OK. Yes. My name is Nilda Grudza. I am an only child. My parents are Jennie and Morris Buccello, and they have been living with us about 2 years. When I say “we,” I mean my husband and two grown sons.

My mother is 75 years old, and she has Alzheimer’s disease. She is barely ambulatory and is incontinent, having been in diapers for about 4 years. She will at times feed herself, but now she doesn’t always do that. Other than that, she has to have everything done for her. She doesn’t communicate.

My father is 84 years old, and he is a diabetic. He requires insulin shots. He is a heart patient. He has had two heart attacks. The biggest problem now is that his heart is greatly enlarged and it causes him to go into heart failure very often. It seems the episodes of heart failure get closer and closer. He is partially blind. He has glaucoma and cataracts. He has rheumatoid arthritis, and he is also hard-of-hearing. He has needed skilled care and therapy at various times after the different hospitalizations.

I am the primary caregiver, and we have been taking care of my parents since my father’s first heart attack 15 years ago. With the passing of time, the responsibilities have greatly increased. I have used home health aides at various times for a period of about 4 years, and some of the problems that I have experienced are as follows:

One time during the hottest week of that particular summer—my mother ended up in the hospital due to a case of severe dehydration because the aide did not give her enough liquids and told my father not to do so because it was too much of a mess for her to clean up when she came back in the morning.

I didn’t instigate any action or anything like that against the agency, but I did inform them as to what had happened. I felt that I should tell them this. And when my mother came home from the hospital, I called the agency to resume service. I was told that my mother had been dropped. They didn’t bother to give me an explanation and they had not bothered to let me know during the period that she was hospitalized that they were going to drop her.
Another time, my mother was impacted—it was a bowel impaction—for at least 2 weeks. She had a lot of pain. The aide failed to tell me that she hadn’t had a bowel movement for quite a while. I found out because I brought my mother home to be with me, and during that time she moaned in pain for 5 nights.

Another aide pushed my mother around and would yell at her for not doing what the aide said. My mother is incapable of following instructions, and screaming at her would really have no good effect other than just to frighten her and confuse her. She has a very docile, sweet nature. She has never become violent or aggressive, and my father did tell that aide at that time not to treat my mother that way. When I found out about it, I had her services terminated.

A lot of times my mother would have bruises on her, particularly her arms. Her skin often had sores and scratches on it. She has an apron stomach, and the area under the stomach would become slimy and have a foul odor due to improper washing. She also had a skin condition which was diagnosed as pemphigus, and this would occur frequently. I am not really certain that this was due to improper washing, but I do know that in the time that she has been living with us she has only had this condition flare up one time, and it was very minimal.

They didn’t wash her feet or her hair. They didn’t clean her fingernails or toenails. They wouldn’t do things like these things. I would have to do these things. I know they are not allowed to cut nails. And one aide rarely, if ever, used soap to wash my mother. It was my impression that she stood her in the tub and hosed her down, and that was it. The basis for this is because the bar of soap provided wasn’t going down. The only time it seemed to be used was when I washed my mom. So I assume she wasn’t using the soap.

There was another incident where an aide wasn’t feeding my mother. My mother became very weak, and upon questioning my father, I realized that she wasn’t getting fed the way she was instructed to.

There were other incidents as well. And I would be happy to answer any questions. Thank you.

The CHAIRMAN. Well, Mrs. Grudza, I want to put this in the right perspective. The things you spoke about, the failures you spoke about, of adequate care for your mother in particular, occurred before you brought them to your home 2 years ago. What kind of timespan are you talking about? Did the problems occur just before you brought them home?

Mrs. GRUDZA. No. They had been going on—as far as my mother is concerned, at least 7 years or so. That is approximately how long she has needed custodial care.

The CHAIRMAN. At least 7 years?

Mrs. GRUDZA. Yes. And at the time, I was working, and I would run back and forth to the house. I maintained my job. After I brought my parents home to live with me, which was approximately 2 years ago, I quit my job with the intentions of staying home to just take care of them. But then my circumstances changed, and I am back at work again, so I do need to rely on help.

The CHAIRMAN. Well, you are now having help again?
Mrs. GRUDZA. I am having help now. It is 4 hours a day. It's not through an agency, though.

The CHAIRMAN. All right. Now, your mother has Alzheimer's, and she is now 75 years old and is really incapable of taking care of herself.

Mrs. GRUDZA. Correct.

The CHAIRMAN. And needs attention all the time then?

Mrs. GRUDZA. Yes.

The CHAIRMAN. That is, constantly?

Mrs. GRUDZA. Yes.

The CHAIRMAN. And your father is 84 years old.

Mrs. GRUDZA. Yes.

The CHAIRMAN. You cannot give her much attention or much help, I assume. He has a bad heart condition and he is diabetic; is that true?

Mrs. GRUDZA. That's correct. And he is in the hospital now.

The CHAIRMAN. He is now in the hospital. When he is at home, what can he do?

Mrs. GRUDZA. Really, nothing.

The CHAIRMAN. Nothing.

Mrs. GRUDZA. It was okay for a time because if something really bad happened, my father could get to the phone and dial "operator." But it has been a tremendous concern of mine in the times that I have left them because he is at the point where he needs somebody to watch him.

The CHAIRMAN. Yes. I see. I can understand that. During the roughly 5 years when your mother and father were not at your home, how much home care did they have? Was it for 8 hours, 10 hours a day, or how long?

Mrs. GRUDZA. My mother would have needed care around the clock if it hadn't been for the fact that my father was there and he was better then. It's hard to put in terms of hours. We had different situations occur. We had an aide that would come for a time in the morning and then come back in the afternoon, in between I would run back and forth and my sons and my husband helped. We would take turns going back and forth. I am sorry I can't be exact as far as the actual time.

The CHAIRMAN. How much did this cost?

Mrs. GRUDZA. The first aide that we had was after my mother's hospitalization for the dehydration episode mentioned previously. The social worker at the hospital called me and referred an agency to me. At that time the State paid a percentage, and my father was required to pay the rest. The State was paying two-something an hour; my father was paying four-something an hour.

The CHAIRMAN. Have you had assistance? Did the State pay part of the bill? Have you had any assistance out of Medicare?

Mrs. GRUDZA. No. The only assistance we have had as far as Medicare is concerned are the times when my father came home from a hospitalization and needed skilled nursing care. They would come out, check his vital signs, and so forth, and leave. That was for a temporary period of time.

I have not been able to get any kind of assistance at all as far as my mother is concerned because she has Alzheimer's, and you cannot get any benefits at all for her needs. If Alzheimer's is men-
tioned, you can't get any help as far as the financial end of it goes. I tried to get therapy for her one time. I felt that since I was working, it would be good to get a therapist to come out to perhaps move her arms and legs to help the muscles, and perhaps keep them from deteriorating, so I inquired about it, and they said, "Well, sure, you can get all the therapists you want, but you have to pay for it. Medicare won't pay for anything as far as she goes with regard to Alzheimers."

The CHAIRMAN. Now, who is paying all the bills? As I understand it, you are working again.

Mrs. GRUDZA. Yes.

The CHAIRMAN. And you need somebody just for 4 hours a day?

Mrs. GRUDZA. Well, that is the way it has been up to now, but I am not going to be able to continue that way because right now my father is very ill. As a matter of fact, we almost weren't able to come here.

The CHAIRMAN. You said he is in the hospital right now?

Mrs. GRUDZA. He is in a hospital and he took a turn for the worse. I am not going to be able to continue that way because right now my father is very ill. As a matter of fact, we almost weren’t able to come here.

The CHAIRMAN. Are you paying all the bills? As I understand it, you are working again.

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The CHAIRMAN. You need somebody just for 4 hours a day?

Mrs. GRUDZA. Yes.

The CHAIRMAN. Four hours a day.

Mrs. GRUDZA. That’s correct. Yes.

The CHAIRMAN. And this is going to have to be increased?

Mrs. GRUDZA. Yes, it will.

The CHAIRMAN. And are you getting whoever is helping you at home with your parents through an agency or not?

Mrs. GRUDZA. No. No.

The CHAIRMAN. Is there a reason for that?

Mrs. GRUDZA. Yes, there is. Because the worst experiences that I have had have been the aides that were sent from agencies. And one of the biggest things is they tell you that they will have a replacement if the person cannot come out to the house for weather or whatever reasons, but I have never once had them send a replacement.

When I was working the "no-shows" occurred frequently. The longest period of time where this happened, was about a 2½ week period in which my father would call me at 12 or 1 p.m., each day.
The aide was to have been there, at about 8 in the morning. He would wait. No one would call him. No one would call me to say that there was no one coming to the house.

My father would call me at work and say, "Nobody came to take care of mom." And then I would punch out, go home, and take care of my mother myself and do what I had to do, and then I could either come back to the job or else just stay at home for the rest of the day.

Now, the only reason that I could do that was because I worked in a doctor's office and had the kind of job where as long as I got the work done it was OK. I was responsible for certain things, but I really had to put pressure on myself to get everything done. I had to do my job and my responsibilities in a lesser amount of time to make up for the time lost in caring for my mother.

The CHAIRMAN. Thank you very much, Mrs. Grudza. Your description of what is needed to take care of your parents is very lucid and very understandable. I hope you are successful, and we will try to be helpful on this end to ease the way so that people like yourself and your parents and others throughout the country might have a better shot, a better chance.

Mrs. GRUDZA. Thank you very much.

The CHAIRMAN. Thank you.

We are going to hear from providers of home health care now: Mrs. Cathy Beard, registered nurse from Virginia; and Mrs. Barbara Lutton, a registered nurse from Michigan.

Ms. Beard, I believe you are first. Please proceed.

STATEMENT OF CATHY BEARD, REGISTERED NURSE, FROM THE STATE OF VIRGINIA

Ms. Beard. I am a registered nurse who, having moved from California with experience only in the hospital setting, found employment with a home health agency and worked in two capacities, initially as a visiting nurse. Having become very disillusioned by that aspect, I then began working private duty with patients in the homes. Subsequently, I went to work for a second home health agency, hoping that the conditions would be somewhat improved, and found out very quickly that that would not be the case.

There have been a number of incidents that occurred during the total of 2 years that I have actually done private duty nursing. The second agency for which I worked hired me with no interview. I filled out an application in April, heard nothing from them until August when, one day the telephone rang, and I was told that I was needed immediately. They only had verification that I was a registered nurse.

I was told by telephone to go to a certain address, meet a patient who was being transported home by ambulance from the hospital with terminal cancer and a gastrostomy tube requiring a pump, a continuous feeding pump in order for him to get the required nutrition.

I had assumed that I would be met by a field supervisor who would assist in setting up the patient equipment. This required setting up a hospital bed, a tremendous amount of supplies, not to mention the feeding pump. The patient arrived home via ambu-
lance with no one to assist. I arrived at the same time, and this, keep in mind, was having been hired by an agency that never had laid eyes on me.

I had no charts. I had no protocol for which to set up this case. He arrived home with a tube feeding pump which was an engineering nightmare and I spent 2 hours of concentrated effort with many mistakes in order to figure out its functioning. There were many incidents with the tube feeding pump when the patient instead of receiving a controlled amount of tube feeding over a 24-hour period, a whole liter of tube feeding dumped into his stomach all at once, caused by inept nurses. He was dying of cancer of the esophagus, which had since metastacized through his entire intestinal tract.

The CHAIRMAN. Was there family there?
Ms. BEARD. A wife.
The CHAIRMAN. A wife.
Ms. BEARD. A wife who at first had a great faith that the nurses would come in and care for her husband. She became disillusioned, which is always the case, and frightened. There were several additional incidents in this particular case, one in which the gastrostomy tube plugged. In order to unplug a gastrostomy tube, one uses irrigation suction with a sterile syringe. The agency refused to bring me an irrigation set, saying that it could wait until the next day. Now, this patient was emaciated, and in my view could not survive 24 hours without nutrition. So I was forced to improvise with an oven roast baster and tap water, which fortunately was successful. We were able to resume his tube feedings.

The CHAIRMAN. Ms. Beard, how long have you been a nurse?
Ms. BEARD. Six years.
The CHAIRMAN. Six years.
Ms. BEARD. Yes.
The CHAIRMAN. And you were hired by this agency over the telephone? Do I understand your correctly?
Ms. BEARD. Basically, yes. I had been to the agency and filled out an application and handed it to a receptionist.
The CHAIRMAN. Oh. Had you identified yourself as a registered nurse by any documents, or was it just your word?
Ms. BEARD. They did see my valid Virginia registered nurse license.
The CHAIRMAN. All right. Then you were called on the telephone and engaged for this particular patient.
Ms. BEARD. Yes.
The CHAIRMAN. You were only one nurse of several, I suppose? Was this around-the-clock nursing?
Ms. BEARD. Yes, it was, sir.
The CHAIRMAN. So you were one of four or five that patient would see in a week's time?
Ms. BEARD. It was far more than four or five.
The CHAIRMAN. It was more than that?
Ms. BEARD. Far more. A parade of strangers in and out of their lives. Normally, in the run of a 7-day, 24-hour-a-day period, there may be 15 different nurses sent on a case who know absolutely nothing about the situation and depend entirely on the preceding
nurse for a very brief and usually inadequate orientation to the case.

One afternoon, I was relieved by a nurse who was clearly inebriated or under the influence of drugs. She was incoherent, could not concentrate, and had a very glazed look on her face. I called the agency and reported her. They did nothing about it, and she was sent back the following day, and in my opinion would probably have continued to be sent back except that the family called and refused to have her back.

There were many incidents of nurses that did not show up, who didn't call, didn't report that they would not be coming.

The CHAIRMAN. Is this all on this one patient?

Ms. BEARD. No.

The CHAIRMAN. This is your experience.

Ms. BEARD. This patient and many other patients. Yes. The same scenario time and time again. One morning when I arrived for work, I found out that the night nurse had left 2 hours previous to my arrival.

The CHAIRMAN. Who paid you?

Ms. BEARD. The agency.

The CHAIRMAN. Just one agency?

Ms. BEARD. Two agencies for which I worked.

The CHAIRMAN. You had experience with two agencies?

Ms. BEARD. Absolutely.

The CHAIRMAN. Let's see, are you from Michigan?

Ms. BEARD. No. From Virginia.

The CHAIRMAN. You're from Virginia.

Ms. BEARD. Yes.

The CHAIRMAN. So in both instances they were Virginia agencies?

Ms. BEARD. Yes, they were.

The CHAIRMAN. Who do you think should be in charge? Who should correct the agency?

Ms. BEARD. Within the agency there has to be an organizational restructuring, but I believe there should also be an independent Government-appointed agency to assess situations.

The CHAIRMAN. Do you know who paid the agencies? Where did the money come from that paid them?

Ms. BEARD. Well, when I was there as a visiting nurse, the main thrust of our patients was Medicare and a few Medicaid patients. The private duty sector was paid primarily by private insurance.

The CHAIRMAN. By private insurance.

Ms. BEARD. I believe so, yes.

The CHAIRMAN. Well, it's the same agency that handles a variety of patients, and so the payments to cover all that comes from a variety of sources; is that right?

Ms. BEARD. A variety of sources, including the patients themselves when their insurance benefits expire. In fact, there was a situation in which the agency refused to provide care for a patient with muscular dystrophy who had a tracheotomy and was on a ventilator, until the wife arrived a week in advance with a check to pay for the following week's care. If they did not arrive with the check, they did not get the care.
The CHAIRMAN. You worked for two different agencies, and nei-
ther one had a training program or an indoctrination type of pro-
gram?
Ms. Beard. Oh, absolutely not. No screening whatsoever.
The CHAIRMAN. No screening?
Ms. Beard. No. One of my first cases with one of the agencies
was a ventilator patient who had Lou Gehrig's disease, also Alzhei-
mer's disease, I had never had any ventilator training.
The CHAIRMAN. You were assigned to do that?
Ms. Beard. In fact to this day I still had no formal ventilator
training and I have been taking care of—ventilator training and I
have been taking care of—

The CHAIRMAN. Is there any preliminary to say to you, "Mrs.
Beard, we are going to send you out, and you're going to take care
of a patient who needs a respirator"? Isn't there any kind of—

Ms. Beard. Orientation?
The CHAIRMAN. Orientation or the simple question, "Are you up
to it? Have you had experience?"
Ms. Beard. No.
The CHAIRMAN. There was none?
Ms. Beard. No.
The CHAIRMAN. None at all?
Ms. Beard. The only training that one would get would be the
training insisted on by the family because—I presume—the agency
would have to pay the nurse for the time that she is in training,
which is not cost effective. So they don't train the nurse. Insurance
companies do not reimburse the agencies for time in training and
care orientation.

The CHAIRMAN. Do you think that's it?
Ms. Beard. I do.
The CHAIRMAN. In other words, it's only for time on the job that
the agency receives some money?
Ms. Beard. Precisely.
The CHAIRMAN. How much did you get per hour?
Ms. Beard. $12.
The CHAIRMAN. $12?
Ms. Beard. $10 if it were not a ventilator case; $11 if it were.
And in one case I was offered $12 an hour in the same case where
the insurance company was being billed $45 an hour.
The CHAIRMAN. $45?
Ms. Beard. Yes, that's correct.
The CHAIRMAN. There is a little margin in there.
Ms. Beard. Somewhat.
The CHAIRMAN. $12 to $45, $33 an hour.
Ms. Beard. Yes.
The CHAIRMAN. All right.

STATEMENT OF BARBARA LU'TTON, REGISTERED NURSE, FROM
THE STATE OF MICHIGAN

The CHAIRMAN. Ms. Lutton, have you had similar experience?
Ms. Lutton. I have had some similar experiences.
The CHAIRMAN. Can you draw that microphone close to you?
Ms. Lutton. I am listed as an in-home health provider, and that is a little off of what I really do. I am employed by the Area Agency on Aging in southwestern Michigan, and I am a case management supervisor, in that I go into the homes of older people who are at risk of nursing home placement, and do an assessment and arrange services that would allow them to stay at home.

The services that are needed are a full range of services, and in that we then broker those services from the different agencies in our area and then monitor the care that is given by these agencies.

I have seen similar incidents as what you have already heard about. We had one particular case where we had a client who had a severe statis ulcer on her ankle, and after some weeks of having the nurse in there on a daily basis to change dressings, the case manager went out herself to look at the situation, and saw that the ulcer, instead of getting better, had increased in size and was much deeper than it had been previously.

In looking at what was done for the patient, the medication that was being used was something that would actually have made the ulcer worse because of the condition of it. The doctor had not been fully notified of what was going on. At the insistence of the case manager, the doctor was informed and a change in care was initiated.

We have seen similar different kinds of problems of what you have already heard about. We were called into one particular case where a home health agency had been involved for a period of 8 months, and when getting there, the home health agency had gotten the Medicare denial the week before, and so even though they had already received over $12,000 in payment for their nursing and nurse's aide visits, they had refused to even make one more visit. And at that point the man had developed a respiratory infection, but because Medicare had pulled out, they wouldn't continue even until we were able to get out there.

What they had been doing for all those months that they were getting paid for was very difficult for us to see. The initial diagnosis that the patient was being treated under had been cleared up many months before, but as long as these agencies can continue documenting anything, they will stay in the cases.

The Chairman. Ms. Lutton, had you seen that patient prior to the instigation or the hiring of that agency to provide the home health care?

Ms. Lutton. No, we hadn't.

The Chairman. Would that have been normal for you to have seen that patient, though?

Ms. Lutton. Well, in a lot of cases we do see the patient first. You know, that's what the ideal situation is for us to set up the services at home when the patient leaves the hospital and arrange those services. We would go in and look at what was actually needed for the patient and broker those services from the agency. We would set up the frequency of the visits, and then we would monitor those visits. Also, when it was appropriate for the nurse to no longer be involved, we would cancel the services.

The Chairman. Well, in that case, you hadn't seen the patient. But Medicare—was it Medicare?

Ms. Lutton. Medicare.
The CHAIRMAN. Medicare was involved. In other words, how many Medicare patients like this, home health care patients, do you actually see? What percentage in—did you say—southwestern Michigan?

Ms. Lutton. Southwestern Michigan. Yes. The clients we see are all over the age of 60. The average age of our clients is between 80 and 82.

The CHAIRMAN. Yes, but what percentage do you see before something is established by an agency to take care of the need?

Ms. Lutton. When we initially started the program, 70 percent of our referrals were that type of referral. But the numbers have decreased down to around 30 percent due to the fact that the local hospital now has formed a home health agency and they refer direction to their home health agency, and the home health agency then provides all the Medicare services to the full extent that they can, and then they sometimes refer them to us at a later time.

The CHAIRMAN. Well, then you are really seeing only a very small portion of them now, less than a third.

Ms. Lutton. Yes. Yes. But even in the cases I have seen—and I think I would be remiss in not mentioning the fact that all home care is not a nightmare.

The CHAIRMAN. Oh, we understand. The cases we have seen today, thank God, while occurring all too often, are not the run-of-the-mill cases, are they?

Ms. Lutton. No, they're not the run-of-the-mill. But they do occur, you know, all too often.

One of the other problems that is very frequent is overserving and inappropriate service. We see cases where home health agencies feel that what is needed in particular cases is what is available in their agency and what is most profitable to them. I can think of one particular case where I went in after the fact again and found that a man had had a massive CDA that was very disabling, had had no follow-up physical therapy in the home. I didn't understand why. In fact, I thought perhaps his wife, who was elderly, might even be confused about what they had received.

I called the home health agency and the home health agency informed me that they didn't have physical therapists that went to that particular area, so they gave him occupational therapy instead.

The CHAIRMAN. Are you telling me, Ms. Lutton, that this occurs very often, infrequently, or what?

Ms. Lutton. As far as Medicare, serving for Medicare inappropriately, I would say that occurs very, very often, yes.

The CHAIRMAN. Like half of the time?

Ms. Lutton. I was talking to Cathy before this meeting and she had a couple of stories that she was telling that would further illustrate what happens. But you know, I was told by an R.N. from my area, you know, ideally what should happen in these cases is the nurse goes to the home when the patient is discharged. She looks at the situation and decides in consultation with the doctor what the frequency of her visits should be there.

Well, she was telling me that before she ever visits the patient, the administrative R.N. tells her how often she is going to be there
by the maximum that Medicare will reimburse. This is the usual operating procedure. It isn’t something unusual.

The CHAIRMAN. In other words, the dollar comes first and the dollar comes through Medicare.

Ms. LUTTON. That’s right, they’re gone.

The CHAIRMAN. And when the dollars run out, “To hell with the patient”?

Ms. LUTTON. Yes. And in those cases, then sometimes they get referred to us and we do have some money under the Older Americans Act that we can provide a certain amount of services. But the ideal is for us to be able to look at the picture before the nurse ever gets there and set up how often they should be going in.

We have two, we’re down to two agencies in the area where we are now, and those two agencies are both telling us now—well, one particular case here a while back, I needed to have blood drawn and there wasn’t a mobile lab to draw blood in that area. So I had to call the home health agency to come out to draw the blood.

The CHAIRMAN. Now, this is the agency that is run by the hospital?

Ms. LUTTON. This particular one was not, no.

The CHAIRMAN. All right. This is the separate one.

Ms. LUTTON. Yes.

The CHAIRMAN. All right.

Ms. LUTTON. But all of the agencies will tell you they cannot make a one-time visit. So if they come out to draw blood, they then have to make multiple visits. And so to do that, some type of monitoring, teaching, something is fabricated to allow continued Medicare payments.

The CHAIRMAN. So you have got two agencies that you are talking about. One is a private agency; is that right?

Ms. LUTTON. We have two agencies in our area now. Previously we had many. Our program has been in existence for 4 years, but because of the fact that the hospital now has their own home health agency, all of their cases are funneled to their own agency.

The CHAIRMAN. Well, is that a good agency?

Ms. LUTTON. It's just like all the other agencies. You know, I am not here to say bad things about that agency.

The CHAIRMAN. What do you mean you’re not here to say bad things? You are telling us bad things about them. Now I am trying to separate out which agency is bad. Are they both bad? Is the one from the hospital a good agency or not?

Ms. LUTTON. The two agencies that are left in our area, I consider them both to be adequate agencies. They are typical agencies.

The CHAIRMAN. Well, is that good or bad?

Ms. LUTTON. All agencies have good and bad.

The CHAIRMAN. Good and bad.

Ms. LUTTON. Right. You know, I have seen much very good professional care; I have also seen some incidences of poor-quality care. I have seen nurse’s aides that don’t show up and don’t bother to call. You know, when you get one to two baths a week, your nurse’s aide not showing up is a big deal. You know, these family members that you have heard talk about what they go through to try to take care of their family, the family members depend upon that homemaker. They depend upon that home health aide being
there on specific days. There are supposed to be days when some-
one else is there when they don’t have to.

The CHAIRMAN. Ms. Lutton, you only look at 30 percent of the
patients who need home care. That means the other 70 percent are
looked at by somebody else. Two agencies are involved. One is run
by a hospital. You are telling me that there is good and bad in both
of these agencies, including the one that is run by the hospital.

Who is in charge of all this? You are not in charge. You only see
30 percent of them. Is there anybody in charge?

Ms. Lutton. The monitoring of what is going on in these agen-
cies is between the administrators of the agencies and their con-
scences.

The CHAIRMAN. And their consciences. In other words, the ad-
inistrator of the home health care agency is in charge, and
nobody checks.

Ms. Lutton. Not as far as I know.
The CHAIRMAN. All right.

Ms. Lutton. I really don’t know of any other.
The CHAIRMAN. There is no procedure where, in your area,
southwest Michigan, where you look at any home health care
agency after it is in place? You see 30 percent of them before they
are in place. Do you ever see any of them after it has been set up?

Ms. Lutton. Sometimes yes. We go in after the fact many times.
The CHAIRMAN. Well, what triggers that?

Ms. Lutton. Usually, when the Medicare money is gone.
The CHAIRMAN. Oh. The money has run out, and somebody has
to fill the gap.

Ms. Lutton. Yes.
The CHAIRMAN. Has to come in and provide the care.

Ms. Lutton. Yes.
The CHAIRMAN. Can a patient, if they are capable, call somebody
to say, “I am just not getting along. I am not getting the right kind
of care. I am just not making it”? Is there anybody to call?

Ms. Lutton. Not that I know of.
The CHAIRMAN. Could the family call somebody? Maybe they
have more time for the telephone or handle the telephone better.
Could the family call somebody?

Ms. Lutton. There is no one that I know of.
The CHAIRMAN. Thank you. That is a sad situation.
Senator Burdick, do you have any questions?

Senator Burdick. I have one or two, Mr. Chairman.
Welcome to the committee.

Ms. Lutton. Thank you.

Senator Burdick. I presume I will address this question to both
of you since you are together, or singly, whatever way you want.
We currently have a nursing shortage in many areas of North
Dakota, and primarily in acute-care settings. Are you finding that
adequate numbers of nurses are pursuing home health as an area
of practice?

Ms. Beard. You said adequate numbers?

Senator Burdick. Yes, that’s the word, “adequate.”

Ms. Beard. I believe that a great many of the people who pursue
the home health aspect are nurses who have become disenchanted
by the profession, professional burnout, nurses who are transients,
nurses whose first priority is family and homemaking, and who choose to make a minimal commitment to health care.

Hospitals require tremendous dedication and a lot of time, not to mention weekends, night shifts, and so forth. The appeal of home health care is that nurses are recruited on the promise that they can work whatever shift whatever day they want. They interpret that as, in my view and from my experience, meaning that there is an army of nurses standing in the wings ready to go in and take the shift that they have decided they don’t really want.

In other words, they make a commitment to work a shift, and for whatever reason, they don't show up. There is an attitude/responsibility problem on the part of registered nurses, a serious lack of commitment to giving good, adequate care. And I think that is why nurses are deserting the ranks of the hospital, which have much more stringent controls, to work in the homes, where they can do their own thing without supervision.

There is no supervision. There is an occasional supervisor who drops by, possibly once every 2 to 3 weeks, asking how it's going. You say, "fine." The supervisor leaves some time slips, and is gone.

Senator BURDICK. Then, in answer to my question, there are adequate numbers?

Ms. BEARD. Yes.

Senator BURDICK. But not adequate in the way it's managed?

Ms. BEARD. Correct.

Senator BURDICK. Is that correct?

Ms. BEARD. Correct.

Ms. Lutton. I have no answer for that. I really don't know if the home health agencies in our area are having problems recruiting enough nurses or not, Senator Burdick.

Senator BURDICK. There have been many major changes in the health care system resulting in many elderly patients being discharged from the hospitals to their homes, "quicker and sicker." What do you think are the major impediments to providing high-quality care in the home setting? Either one or both of you may respond.

Ms. Lutton. Well, the only solution that I can possibly see is some type of monitoring device that is put in place, and this has got to be someone that is actually in the home, someone that has no financial gain as far as what services are recommended and what services are set up, and someone that has control over what is reimbursed and what is not reimbursed.

It seems like a strange system to me right now that has a shopkeeper deciding what quantity and what quality of merchandise his customer needs, and that is what is happening in the health care system now.

Senator BURDICK. Well, you are really referring to the supervision, general management. Is that what you are saying?

Ms. Lutton. Yes.

Senator BURDICK. It is lacking.

Ms. Lutton. Yes. I am saying that someone has to go in and look at those cases and tell the home health agencies what is needed. Someone has to go back and monitor what was ordered is in place, and someone has to follow those cases as long as the home health agencies are involved, and it needs to be someone independ-
ent of the home health agencies, that has no financial gain in de-
ciding that a nurse is needed every day or a nurse is needed only
once a week or a physical therapist is needed by this patient.

We had some cases in another county where we had opened
them to maintenance services with money under the Older Ameri-
cans Act to homemakers and home health aides, but we purchased
those services through one of the agencies in that county. Repeat-
edly, they would call and say that they thought that they could put
a nurse in there for us. It wasn’t that this patient has had some-
thing acute come up that needs a nurse, it’s something, “We think
we can justify a nurse.” Repeatedly, we were arguing with them
about adding services that really were not needed.

Senator Burdick. Now, you testified that there should be some-
one to do these things. Who is that someone?

Ms. Lutton. Well, the area agencies on aging now—not all of
them, but a large number of them—do have care management pro-
grams such as ours. This is what we have tried to do in the area in
our area. But we have worked on a cooperative basis, and some-
times if you try to limit the amount of service that a health care
provider is sending in there, the cooperation gets rather thin.

Then there are cases, too, when we need to be able to assure that
provider that you will, yes, get paid for this. In the case of a situ-
ation where the health care providers are all telling us they can’t go
in because they are not going to get paid for just one visit, I have
to go for 2 weeks, three times a week. We need to have the right to
say, “You will get paid for this one visit. Come make the one visit.
That is all that is needed.”

Senator Burdick. Ms. Beard, do you have anything to say about
this subject?

Ms. Beard. I also believe that there needs to be an independent
monitoring agency. We need to legislate for minimum standards
within the home health care industry, ongoing training, updating
of skills for nurses, matching nurses’ skills with patient needs, case
orientation, and the basic screening of nurses, testing for skills,
with a full-time field supervisor whose primary function it would
be to monitor home cases.

Senator Burdick. Well, this full-time field supervisor, who would
they be responsible to and who would provide for them?

Ms. Beard. I believe that it would be the responsibility of the
agency to employ the field supervisor who would be overseen, per-
haps, by an independent agency in addition to his or her private,
for-profit agency. But there does need to be an independent over-
seer.

It is a large, profit-making industry, which hires nurses who
have “R.N.” behind their names, that being all this industry is con-
cerned with is profit.

Senator Burdick. Well, the question I have asked both of you
witnesses this morning falls under one category. There seems to be
a lack of supervision.

Ms. Beard. True.

Senator Burdick. Thank you, Mr. Chairman.

The Chairman. Thank you, Senator.

I am going to make an assumption, and if I am wrong, please
correct me. What you are saying is that somebody ought to be in
charge, and it either has to be the Federal Government or the State Government. We have heard from five different States today that were not in charge—

Ms. BEARD. Right.

The CHAIRMAN [continuing]. And obviously the Federal Government is not in charge. Now, can you just tell me yes or no: Do you believe it ought to be State Government or Federal Government? You can't say yes or no to that, but just say State or Federal. Do you believe it ought to be State Government?

Ms. BEARD. I believe it should be—no.

The CHAIRMAN. What should it be?

Ms. BEARD. Federal.

The CHAIRMAN. Federal.

Ms. LUTTON. I believe that is the only way it would be uniform for it to be—it has to be the same everywhere, the same type of monitoring. So I guess I would have to say it would be Federal.

The CHAIRMAN. All right. I guess we can't shirk our duty here. We are the Federal Government in this room and throughout all this surrounding area here on Capitol Hill. I think you are right, Ms. Lutton, it has got to be uniform between the States, and so I guess the responsibility starts with the Federal Government.

I want to thank both of you for your testimony. We are going to hear from the Administration, the Executive Branch of the Federal Government, as our next witnesses.

Thank you both very much for providing us your own experience and your own obviously professional opinion on these matters.

To testify for the Administration is the Deputy Commissioner on Aging, Administration on Aging, Mr. Charles Wells; and the Associate Administrator for Operations in the Health Care Financing Administration, Mr. Louis B. Hays.

Let's see, Mr. Wells, would you swing a little bit over to the center? Good. Thank you.

I believe we will hear from you first, and please summarize as rapidly as you can.

STATEMENT OF CHARLES WELLS, DEPUTY COMMISSIONER ON AGING, ADMINISTRATION ON AGING

Mr. WELLS. Good morning, Mr. Chairman. I am pleased to have the opportunity to discuss the Older Americans Act and the role which the Administration on Aging is playing in providing home care services to America's elderly citizens.

The Administration on Aging is proud of the contributions made by the national network of State and area agencies on aging to improve the quality of life for all older Americans. The programs supported under the act are meeting a number of social, nutrition, and health-related needs of older Americans. In particular, State and area agencies on aging are addressing the needs of large numbers of vulnerable older Americans who are in need of home care services. These agencies have made great strides in enabling older Americans to remain independent as long as possible.

More than 149 million congregate meals were provided for older persons and their spouses. Another 79.8 million meals were provided to homebound elderly. Supportive services were provided to
more than 9 million older Americans in the broad categories of access, in-home, and legal services. And finally, a wide range of services, many of them in-home services, were also provided to elderly Indians under Title VI of the act.

The Administration on Aging has also provided support for a range of research, demonstration, and training activities focused on home care for the vulnerable elderly. This effort includes a large number of projects designed to help families and other persons who care for the frail and impaired elderly in their homes and communities. For example, 22 demonstration projects are developing model Statewide and local dissemination campaigns to inform and educate caregivers about the most effective way to carry out their difficult tasks.

Eleven demonstration awards are now widely disseminating knowledge about elder abuse and demonstrating Statewide efforts to prevent and treat this problem. Fifteen demonstration awards are drawing special attention to the needs of Alzheimer's patients and their family members and caregivers, focusing on respite care models, family support groups, caregiver training, and improved family-based care.

Finally, we have devoted major resources and energies to developing responsive community systems for older persons. In 16 model projects we are addressing such important topics as guardianship, post-hospital care, mental health, and community-based care.

The Administration on Aging has also developed a generic caregiver booklet designed to provide information to informal caregivers to vulnerable older people, particularly caregivers and concerned relatives who may live in different parts of the country than the older person. This tool enables them to access services in geographically distant locations. We have been successful in working with a number of private-sector groups to reproduce and distribute this guide to their employees, their customers, and the public at large.

The Administration on Aging is also very much committed to the quality of services that are provided to older persons and their families. However, we do recognize that quality assurance for in-home and supportive services involves many complex issues. Under our programs, States are provided considerable flexibility in determining which services are to be made available, how service delivery should be organized, to whom services should be provided, and how quality should be maintained.

Given the wide range of social services and the variation among States and communities and the availability, organization, and delivery of services, we feel that State and local entities are the most important locus for setting standards and monitoring provider performance. We have demonstrated our commitment to the issue of quality in home care by funding the American Bar Association project which resulted in the report “The Black Box of Home Care Quality.” This report, widely disseminated to State agencies on aging and others, has focused needed attention on this important topic.

The Administration on Aging is helping build on this knowledge base by working to assist State and area agencies to improve the quality of home care for older persons funded under the Older
Americans Act. In this regard, we are supporting a project with the Ohio Department of Aging to design, implement, and evaluate a model quality assurance program for in-home services for older people. Under this effort, quality assurance standards will be designed for such services as homemaker, home health, personal care, home meals, and case management, and will address quality in terms of structure, process, and outcomes.

A second demonstration project being carried out for the Clackamas County, Oregon, area agency on aging will replicate and test a local-State quality assessment program. Upon the completion of these projects, the Administration on Aging will assure widespread dissemination of these standards and encourage and assist State agencies in their implementation.

Title IV education and training projects provide support for career preparation of health and social service professionals as well as continuing education, training, and staff development for professionals and paraprofessionals who work with the elderly. By increasing the competencies of these personnel, a higher degree of quality care for the elderly can be provided in a variety of settings: hospitals, nursing homes, boarding care facilities, and in their own homes.

The Administration on Aging has provided support for a number of training projects specifically focused on quality in-home services, including paraprofessional training for providers of home care services in rural Virginia, training for rural service providers and family caregivers of homebound elderly at Atlanta University, and continuing education at New Mexico State University to increase the knowledge and skills of home health aides as well as managers and supervisors of home health agencies.

In addition, Mr. Chairman, the Administration draft bill for the reauthorization of the Older Americans Act includes provisions that we believe will strengthen the Act in helping to assure the provision of quality care to those elderly in greatest need. These provisions include increased emphasis on services for older persons threatened with loss of independence who are residing at home, in hospitals, or in long-term care facilities.

A second point is waivers for innovative community programming and fees for services to generate new resources and the opportunity to expand the transfer of supportive and nutrition services funds.

Through these and other activities, the Administration on Aging is committed to continue to support State and area agencies on aging in assisting vulnerable and frail older persons find appropriate help and maintain their independence. We will continue to work toward developing and refining community service systems in which all of the pieces support the whole, where all of the players are aware of and support each other. These efforts will focus on strengthening the roles of State and area agencies on aging as systems builders, catalysts, information referral centers, and brokers of services.

The Administration on Aging will continue to place emphasis on activities such as in-home services and to support State and area agencies on aging in building responsive systems of home-based care. In this regard, we will also assist State and area agencies to
become more involved in the development of in-home quality assurance standards. We believe such standards are important and needed. In this regard, we believe that such standards must address the sensitivities of individual States and communities and can best be determined by each State in addressing its own special needs related to home care.

I want to thank you, Senator Melcher, for the opportunity to share some of the important accomplishments of the Older Americans Act, especially concerning in-home care and services for the vulnerable elderly. We thank you for your support of programs for the Nation's elderly citizens and their families. This Administration is deeply committed to improving the quality of life with quality services for all older Americans.

Thank you.

[The prepared statement of Mr. Wells follows:]
GOOD MORNING, SENATOR MELCHER AND MEMBERS OF THE SPECIAL COMMITTEE ON AGING. I AM PLEASED TO HAVE THE OPPORTUNITY TO DISCUSS WITH YOU TODAY THE OLDER AMERICANS ACT AND THE ROLL WHICH THE ADMINISTRATION ON AGING (AOA) IS PLAYING IN PROVIDING HOME CARE SERVICES TO AMERICA'S ELDERLY CITIZENS. I CAN ASSURE YOU OF OUR COMMITMENT IN PROVIDING QUALITY HOME CARE SERVICES TO THOSE OLDER PERSONS IN GREATEST NEED IN OUR SOCIETY.

THE OLDER AMERICANS ACT (OAA) PASSED BY THE CONGRESS NEARLY 22 YEARS AGO IS AN IMPORTANT PIECE OF LEGISLATION THAT HAS BEEN ENORMOUSLY SUCCESSFUL IN SERVING THIS NATION'S RAPIDLY GROWING OLDER POPULATION. IN 1965, THE APPROPRIATION LEVEL WAS ONLY $7.5 MILLION. IN FY 1987, THE OLDER AMERICANS ACT APPROPRIATIONS TOTAL $724.7 MILLION.

THE ADMINISTRATION ON AGING IS VERY PROUD OF THE CONTRIBUTIONS MADE BY THE NATIONAL NETWORK OF STATE AND AREA AGENCIES ON AGING TO IMPROVE THE QUALITY OF LIFE FOR OLDER AMERICANS WITH BOTH THE SUPPORTIVE AND NUTRITION SERVICES AUTHORIZED BY THE OLDER AMERICANS ACT.

WE BELIEVE THAT HELPING OLDER PERSONS TO REMAIN INDEPENDENT CAN BE ACHIEVED BEST THROUGH WORKING WITH STATE AND AREA AGENCIES TO BUILD LOCAL SYSTEMS WHICH ARE HIGHLY VISIBLE.
EASILY ACCESSIBLE TO OLDER PERSONS, AND RESPONSIVE TO THE NEEDS OF OLDER AMERICANS, PARTICULARLY THE MOST VULNERABLE. COMMUNITY SYSTEMS MUST ALSO BE TAILORED TO MEET THE NEEDS AND SPECIAL CIRCUMSTANCES OF INDIVIDUAL COMMUNITIES. THESE SYSTEMS, TO BE SUCCESSFUL, HAVE TO BE SUPPORTED BY A WIDE RANGE OF PUBLIC, PRIVATE, VOLUNTARY, AND RELIGIOUS ORGANIZATIONS AS WELL AS BY DEDICATED INDIVIDUALS.

WE ARE CONTINUING TO WORK TOWARD DEVELOPING AND REFINING SYSTEMS IN WHICH ALL OF THE PIECES SUPPORT THE WHOLE, WHERE ALL OF THE PLAYERS ARE AWARE OF AND SUPPORT EACH OTHER. THESE EFFORTS WILL FOCUS ON STRENGTHENING THE ROLES OF STATE AND AREA AGENCIES ON AGING AS CATALYSTS, INFORMATION AND REFERRAL CENTERS, AND AS BROKERS OF SERVICES.

AS AOA BEGINS THE THIRD DECADE OF ADMINISTERING THE OAA, WE ARE UNDERTAKING A CRITICAL EXAMINATION OF NOT ONLY WHAT HAS BEEN ACCOMPLISHED BUT ALSO WHAT REMAINS TO BE DONE. WE MUST OPERATE WITHIN THE FRAMEWORK OF THE CHANGING DEMOGRAPHICS OF THE ELDERLY, WHILE STILL ENSURING THAT THE NATION'S NEEDIEST ELDERLY PERSONS CONTINUE TO RECEIVE THE ASSISTANCE THEY REQUIRE TO REMAIN SELF-SUFFICIENT AND INDEPENDENT WITHIN THEIR OWN HOMES AND COMMUNITIES.

A second major challenge will be to focus our increasingly scarce public resources on those older persons most in need of assistance. Frequently, these persons -- the most vulnerable -- are women, minorities, low income persons, and the very old.

The Title III program has evolved from a program of relatively small community service projects for older persons into a complex and highly differentiated "national network on aging" currently consisting of 57 state agencies and approximately 670 area agencies on aging (AAA) and more than 25,000 local nutrition and supportive service providers.

Three separate Title III allocations are made to the states for (1) supportive services and senior center operations; (2) congregate nutrition services; and (3) home-delivered meals.

Each state makes awards to the area agencies, based upon their approved area plans, to pay up to 85 percent of the costs of supportive services and senior centers and for nutrition services. In most cases, area agencies then arrange with public, nonprofit, and/or proprietary service providers to deliver nutrition and other services described in the area plan. Area agencies monitor these services, plan for future needs and serve as advocates and leaders on behalf of all older persons in their planning and service area.

We are convinced that the services and programs supported under Title III are meeting important social, nutrition, and health-related needs of older Americans. In particular, there are elderly persons who have special social and economic needs who benefit substantially from Older Americans Act programs. It is to these people that our programs must always reach out to help.

This mandate is and has been emphasized in our commitment to target resources to those older persons in the greatest social and economic need and to those most in danger of losing their independence.

Both ADA and the Aging Network recognize and are addressing -- through the programs, services, and special projects supported
UNDER THE OAA -- THE NEEDS OF LARGE NUMBERS OF ELDERLY AMERICANS WHO ARE IN NEED OF HOME CARE SERVICES. ALTHOUGH MOST ELDERLY PERSONS ARE IN GOOD HEALTH AND ABLE TO LIVE INDEPENDENTLY, A SIGNIFICANT NUMBER ARE IN NEED OF SUPPORTIVE AND LONG-TERM CARE SERVICES.

THE NEED FOR HOME CARE SERVICES

THE 1982 NATIONAL LONG-TERM CARE SURVEY PROVIDES A BASIS FOR ESTIMATING THAT IN 1985 APPROXIMATELY 4.5 MILLION (OR 13.9 PERCENT) PERSONS AGE 65 AND OLDER WHO WERE LIVING IN THE COMMUNITY WERE ALSO IN NEED OF SOME HELP WITH THE ACTIVITIES OF DAILY LIVING OR INSTRUMENTAL ACTIVITIES OF DAILY LIVING -- SUCH AS, MANAGING MONEY, MOVING ABOUT OUTDOORS, SHOPPING, DOING HEAVY HOUSEWORK, PREPARING MEALS, TAKING MEDICATION. ACCORDING TO THE SURVEY, ABOUT 3.5 PERCENT OF THE TOTAL ELDERLY POPULATION LIVING IN THE COMMUNITY HAD SEVERE LIMITATIONS. THE NEED FOR ASSISTANCE ALSO WAS FOUND TO INCREASE WITH AGE. THE SURVEY FOUND THAT 12.6 PERCENT OF PERSONS AGED 65 - 74 NEEDED ASSISTANCE WITH PERSONAL CARE ACTIVITIES DUE TO CHRONIC ILLNESS, WHEREAS 45.8 PERCENT OF INDIVIDUALS 85 OR OLDER NEEDED ASSISTANCE.


SERVICES PROVIDED UNDER TITLE III

THE AOA IS VERY PROUD OF THE CONTRIBUTIONS THAT THE TITLE III PROGRAM HAS MADE TO IMPROVE THE QUALITY OF LIFE FOR OLDER AMERICANS AND TO ENABLE OLDER PERSONS TO REMAIN INDEPENDENT FOR AS LONG AS POSSIBLE.
In FY 1983, approximately 149 million congregate meals (serving 2.9 million elderly) were provided to older persons and their spouses.

In FY 1986, 79.8 million home-delivered meals were provided to approximately 671,000 homebound elderly.

More nutrition services are being targeted to homebound elderly each year. Most states are transferring funds out of their allotments for congregate meals and into their allotments for home-delivered meals and supportive services. In FY 1986 alone, $47 million was shifted for this purpose. For some persons, the home-delivered meals program may make the difference in their being able to remain in their own homes.

Under Title III-B of the OAA, three broad categories of supportive services are provided: (1) access services (e.g., transportation and outreach); (2) in-home services (e.g., housekeeping, personal care, and visiting); and (3) community and neighborhood services (e.g., legal services, residential repair, and escort services). The supportive services program is currently serving an estimated 8.9 million or more citizens each year. In FY 1985, 16.3 percent of all Title III-B program participants were minorities and 42.8 percent were low income.

Title VI of the OAA also provides a wide range of supportive and nutrition services to elderly members of Indian tribal organizations. Of the eligible population of about 28,500 elderly, approximately 90 percent participated in nutrition services (30 percent of these at home) and 60 percent received one or more supportive services.

Under Title IV of the OAA, AOA has provided support for a diverse range of research and demonstration projects and training and education activities focused on supportive and
HOME CARE SERVICES. THESE INCLUDE A LARGE NUMBER OF PROJECTS DESIGNED TO HELP FAMILIES AND OTHER PERSONS WHO CARE FOR THE FRAIL AND IMPAIRED ELDERLY IN THEIR HOMES AND COMMUNITIES:

0 AS PART OF AOA'S STRATEGY TO TARGET SERVICES TO THE VULNERABLE ELDERLY, THE AGENCY HAS LAUNCHED AN INITIATIVE TO IMPROVE THE CAPACITY OF CAREGIVERS WHO PROVIDE CRITICAL ASSISTANCE TO FUNCTIONALLY IMPAIRED OLDER PERSONS. THIS ASSISTANCE IS BASED ON THE RECOGNITION THAT GROWING NUMBERS OF VULNERABLE OLDER PERSONS IN THIS COUNTRY ARE CARED FOR IN THEIR HOMES BY FAMILY, FRIENDS, AND NEIGHBORS, AND THAT THESE CAREGIVERS OFTEN HAVE INSUFFICIENT INFORMATION, TRAINING, AND SUPPORT TO PERFORM THEIR ROLES IN A FULLY EFFECTIVE MANNER. DURING FY 1986, AOA FUNDED 22 RESEARCH AND DEMONSTRATION PROJECTS, REPRESENTING A COMMITMENT OF $2.4 MILLION, TO DEVELOP MODEL STATEWIDE AND LOCAL DISSEMINATION CAMPAIGNS TO INFORM AND EDUCATE CAREGIVERS ABOUT THE MOST USEFUL WAYS OF CARRYING OUT THEIR DIFFICULT TASKS. THE PROJECTS WILL IMPLEMENT STATEWIDE AND LOCAL CAMPAIGNS USING TELEVISION, FILM, VIDEOTAPES AND TELECOMMUNICATIONS IN INNOVATIVE WAYS TO REACH THE WIDEST POSSIBLE AUDIENCE.

0 A PROJECT FUNDED BY AOA IN FY 1985 AND CONDUCTED BY THE UNIVERSITY OF KANSAS ESTABLISHED A NATIONAL NEWSLETTER FOR CAREGIVERS CALLED PARENT CARE. THE PROJECT EXPECTS TO BECOME SELF-SUFFICIENT DURING FY 1987.

0 AS PART OF THE CAREGIVER INITIATIVE AND AOA'S LONG-TERM CARE ACTIVITIES, AOA HAS DEVELOPED A GENERIC CAREGIVER BOOKLET DESIGNED TO PROVIDE INFORMATION TO INFORMAL CAREGIVERS OF VULNERABLE OLDER PEOPLE - PARTICULARLY TO CAREGIVERS AND CONCERNED RELATIVES WHO MAY LIVE IN A DIFFERENT PART OF THE COUNTRY THAN THE CARE RECIPIENT. WE HAVE BEEN SUCCESSFUL IN WORKING WITH A NUMBER OF PRIVATE SECTOR GROUPS TO HAVE THEM REPRODUCE AND DISTRIBUTE THIS GUIDE, E.G., LEVI STRAUSS COMPANY (KNOXVILLE, TN), BLUE CROSS/BLUE
SHIELD (JACKSONVILLE, FL.) AND UTAH LIGHT AND POWER
(IN COLLABORATION WITH THE STATE AND AREA AGENCIES ON
AGING IN UTAH).

QUALITY OF SERVICES AND CARE

THE AOA IS CONCERNED THAT THE MOST FRAIL AND VULNERABLE OF THE
ELDERLY -- AND THEIR FAMILIES -- RECEIVE THOSE IN-HOME AND
OTHER SERVICES WHICH WILL ENABLE THEM TO REMAIN INDEPENDENT AND
IN THEIR COMMUNITIES. WE ALSO ARE VERY MUCH COMMITTED TO THE
PROVISION OF QUALITY SERVICES TO EVERY OLDER PERSON AND HIS/HER
FAMILY.

WE DO RECOGNIZE, HOWEVER, THAT QUALITY ASSURANCE FOR IN-HOME
AND SUPPORTIVE SERVICES INVOLVES MANY COMPLEX ISSUES.
STATES HAVE CONSIDERABLE FLEXIBILITY IN DETERMINING WHICH
SERVICES ARE TO BE MADE AVAILABLE; HOW SERVICE DELIVERY SHOULD
BE ORGANIZED; TO WHOM SERVICES SHOULD BE PROVIDED; AND HOW
QUALITY SHOULD BE MAINTAINED. GIVEN THE WIDE RANGE OF SOCIAL
SERVICES -- FROM HOME-DELIVERED MEALS TO PERSONAL CARE -- AND
THE VARIATION AMONG STATES AND COMMUNITIES IN THE AVAILABILITY,
ORGANIZATION AND DELIVERY OF SERVICES, STATE AND LOCAL ENTITIES
ARE THE MOST APPROPRIATE LOCUS FOR SETTING STANDARDS AND
MONITORING PROVIDER PERFORMANCE.

THE TREMENDOUS GROWTH IN THE POPULATION RECEIVING FORMAL HOME
CARE SERVICES AS WELL AS THE INCREASING AMOUNT OF FEDERAL AND
STATE TAX DOLLARS SPENT ON THESE PROGRAMS HAVE RESULTED IN
EFFORTS BY THE DEPARTMENT, MANY STATES, PROFESSIONAL
ORGANIZATIONS AND OTHERS TO REVIEW AND UPDATE INFORMATION ON
THE QUALITY OF CARE AND TO DEVELOP NEW STRATEGIES FOR ASSURING
QUALITY IN-HOME CARE SERVICES TO VULNERABLE PERSONS.

HOWEVER, THE DEVELOPMENT OF NEW STRATEGIES SHOULD NOT BE
LIMITED TO A REVIEW AND REVISION OF FEDERAL AND STATE
STANDARDS. THERE ARE SEVERAL OTHER ELEMENTS WHICH ARE IMPORTANT
IN INFLUENCING THE QUALITY OF FORMAL HOME CARE SERVICES. THESE
INCLUDE STAFF TRAINING; SUPERVISION; INDUSTRY ACCREDITATION;
PROFESSIONAL CERTIFICATION; AND CONSUMER ADVISORY BODIES
(INCLUDING FAMILIES).
A RECENT STUDY COMPLETED BY THE AMERICAN BAR ASSOCIATION (ABA)
AND FUNDED IN PART BY AOA, "THE 'BLACK BOX' OF HOME CARE
QUALITY." OUTLINED A NUMBER OF LEGAL CONTROLS AND ECONOMIC
REALITIES WHICH TRANSCEND THE FORMAL REGULATORY FRAMEWORK AND
INFLUENCE THE NATURE AND QUALITY OF HOME CARE IN SELECTIVE
WAYS. TWO OF THESE IMPORTANT CONTROLS INCLUDE INDUSTRY
ACCREDITATION AND THE CERTIFICATE OF NEED MECHANISM. ALSO, THE
INSURANCE INDUSTRY IS GIVING SERIOUS CONSIDERATION TO MORE
COMPREHENSIVE FORMS OF LONG-TERM CARE INSURANCE, INCLUDING THE
COVERAGE OF HOME CARE. AS A POTENTIAL PAYOR OF HOME CARE, THE
INSURANCE INDUSTRY COULD PLAY AN IMPORTANT ROLE IN DEFINING THE
NATURE AND QUALITY OF HOME CARE SERVICES. THE AMERICAN BAR
ASSOCIATION STUDY ALSO DEMONSTRATES COLLABORATION UNDERWAY
BETWEEN THE PUBLIC AND PRIVATE SECTORS IN EFFORTS TO IMPROVE
THE QUALITY OF HOME CARE.

A DISCUSSION OF HOME CARE SERVICES MUST ALSO RECOGNIZE THE
IMPORTANT ROLE OF THE NON-AGENCY "INDIVIDUAL CONTRACTOR." THE
NATIONAL LONG-TERM CARE CHANNELING DEMONSTRATION, A LANDMARK
TEN-STATE EXPERIMENT SUPPORTED BY THE DEPARTMENT -- INCLUDING
AOA -- CONFIRMED THAT HIGH QUALITY PERSONAL CARE SERVICES CAN
BE GIVEN BY PERSONS CAREFULLY RECRUITED BY FAMILY MEMBERS
THROUGH NEWSPAPER ADS, NEIGHBORHOOD CONTACTS, AND FRIENDS.

THE OLDER AMERICANS ACT REQUIRES THAT EACH STATE PLAN FOR
SERVICES AND UNDERTAKE ACTIVITIES WHICH WILL ASSURE THAT THE
PROVISIONS OF THE OAA AND ALL APPLICABLE STATE AND LOCAL LAWS
ARE MET. THUS, AREA AGENCIES ON AGING HAVE GENERAL OVERSIGHT
OF SERVICES THAT ARE BEING RECEIVED BY OLDER PERSONS IN THEIR
HOMES WITH SPECIFIC MONITORING OF THE PERFORMANCE OF ANY
PROVIDER BEING FUNDED UNDER THE ACT.

UNDER ITS TITLE IV DISCRETIONARY PROGRAMS, THE AOA IS HELPING
TO BUILD A KNOWLEDGE BASE TO ASSIST STATE AND AREA AGENCIES TO
ASSURE THE QUALITY OF HOME CARE FOR OLDER PERSONS. RESEARCH
AND DEMONSTRATION EFFORTS INCLUDE THE SUPPORT OF A PROJECT BY
THE OHIO DEPARTMENT OF AGING, IN CONJUNCTION WITH MIAMI
UNIVERSITY, TO DESIGN, IMPLEMENT AND EVALUATE A MODEL QUALITY
ASSURANCE PROGRAM FOR IN-HOME SERVICES FOR ELDERLY CARE
RECIPIENTS. THE PROJECT WILL ALSO PROVIDE TRAINING AND
GUIDANCE ON QUALITY ASSURANCE PROGRAM STANDARDS AND PRACTICES THROUGH A HANDBOOK AND A REGIONAL CONFERENCE IN OHIO. THIS PROJECT IS SCHEDULED FOR COMPLETION IN LATE 1987.

A SECOND DEMONSTRATION PROJECT, FUNDED BY AOA IN 1986 AND TARGETED FOR COMPLETION AT THE END OF 1987, IS BEING CARRIED OUT BY THE CLACKAMUS COUNTY (OREGON) AREA AGENCY ON AGING WHICH WILL REPLICATE AND RSVP A LOCAL/STATE QUALITY ASSESSMENT PROGRAM.

THE ADMINISTRATION ON AGING WILL ASSURE WIDESPREAD DISSEMINATION OF THE RESULTS OF THESE PROJECTS AND WILL ENCOURAGE STATES TO ADOPT THE STANDARDS, AS APPROPRIATE.

TITLE IV EDUCATION AND TRAINING PROJECTS PROVIDE SUPPORT FOR PREPARATION OF HEALTH AND SOCIAL SERVICE PROFESSIONALS IN GERIATRICS AND GERONTOLOGY AS WELL AS CONTINUING EDUCATION, TRAINING, AND STAFF DEVELOPMENT FOR PROFESSIONALS AND PARAPROFESSIONALS WHO WORK WITH THE ELDERLY. BY INCREASING THE QUALIFICATIONS OF THESE PERSONNEL, A HIGHER DEGREE OF QUALITY CARE FOR THE ELDERLY CAN BE PROVIDED IN WHATEVER SETTINGS OLDER PERSONS ARE FOUND -- HOSPITALS, NURSING HOMES, BOARD AND CARE FACILITIES, AND THEIR OWN HOMES.

AOA ALSO HAS PROVIDED SUPPORT FOR A NUMBER OF PROJECTS SPECIFICALLY FOCUSED ON QUALITY ASSURANCE IN HOME CARE FOR THE ELDERLY. RECENTLY COMPLETED PROJECTS INCLUDE:

- PARAPROFESSIONAL TRAINING FOR PROVIDERS OF HOME CARE SERVICES TO RURAL, MINORITY ELDERLY BY THE SOUTHSIDE VIRGINIA COMMUNITY COLLEGE; AND

- A TRAINING PROGRAM FOR RURAL SERVICE PROVIDERS AND FAMILY CAREGIVERS OF HOMEBOUND ELDERLY AT ATLANTA UNIVERSITY.

CURRENTLY FUNDED PROJECTS INCLUDE:

- A TRAINING PROGRAM AT THE UNIVERSITY OF MARYLAND AT BALTIMORE FOR SOCIAL WORKERS AND IN-HOME AIDES TO FACILITATE COMMUNICATION BETWEEN PHYSICIANS AND THE ELDERLY REGARDING PROPER DRUG USE; AND
A CONTINUING EDUCATION PROGRAM AT NEW MEXICO STATE UNIVERSITY THAT INCREASES THE KNOWLEDGE AND SKILLS OF HOME HEALTH AIDES AS WELL AS MANAGERS AND SUPERVISORS OF HOME HEALTH AGENCIES.

IN ADDITION, MR. CHAIRMAN, THE ADMINISTRATION'S BILL FOR THE REAUTHORIZATION OF THE OAA, WHICH HAS BEEN INTRODUCED IN THE HOUSE AS HR 2085, INCLUDES PROVISIONS THAT WE BELIEVE WILL STRENGTHEN THE OAA IN HELPING TO ASSURE THE PROVISION OF QUALITY CARE TO THOSE ELDERLY WITH GREATEST NEED. THESE PROVISIONS INCLUDE:

1. COORDINATION OF COMMUNITY-BASED SERVICES
   THE BILL WOULD REQUIRE STATE AGENCIES ON AGING TO PROVIDE ASSURANCE THAT AREA AGENCIES WILL FACILITATE THE COORDINATION OF COMMUNITY-BASED SERVICES TO OLDER INDIVIDUALS RESIDING AT HOME, IN HOSPITALS, OR LONG-TERM CARE FACILITIES, WHO ARE AT RISK OF INSTITUTIONALIZATION BUT WHO COULD REMAIN AT HOME IF A FULL ARRAY OF COMMUNITY-BASED AND IN-HOME SERVICES WERE AVAILABLE. THIS WILL REAFFIRM THE CRITICAL ROLE OF EACH AREA AGENCY ON AGING AS A PLANNER/COORDINATOR/CATALYST ON BEHALF OF ALL OLDER AMERICANS.

   COORDINATION OF HOME AND COMMUNITY-BASED SERVICES FOR THE VULNERABLE ELDERLY HAS BECOME AN INCREASINGLY IMPORTANT SERVICE PRIORITY THAT SHOULD BE A REQUIRED ACTIVITY OF STATE AND AREA AGENCIES ON AGING. AREA AGENCIES ARE IN A UNIQUE POSITION TO PROVIDE LEADERSHIP IN COORDINATING THE WIDE ARRAY OF HEALTH AND SOCIAL SERVICES NEEDED BY VULNERABLE ELDERLY PERSONS TO REMAIN AT HOME.

2. WAIVERS FOR INNOVATIVE COMMUNITY PROGRAMMING
   THE BILL WOULD AUTHORIZE THE COMMISSIONER ON AGING TO WAIVE COMPLIANCE WITH ANY REQUIREMENTS OF SPECIFIC SECTIONS OF THE ACT (RELATING TO STATE PROGRAM ORGANIZATION, AREA PLANS, AND STATE PLANS) IN THE CASE OF DEMONSTRATION PROJECTS THAT PROMOTE THE OBJECTIVES OF TITLE III. THE OAA CURRENTLY PROVIDES STATE
AGENCIES WITH THE AUTHORITY TO CARRY OUT DEMONSTRATION PROJFCTS OF STATEWIDE SIGNIFICANCE RELATING TO THE INITIATION, EXPANSION, OR IMPROVEMENT OF SERVICES ASSISTED UNDER TITLE III. HOWEVER, STATE AGENCIES ARE HAMPERED FROM UNDERTAKING EFFECTIVE DEMONSTRATIONS OF COMPREHENSIVE AND COORDINATED SYSTEMS BECAUSE OF THE VARIOUS REQUIREMENTS IN THE CURRENT LAW. FURTHER, VARIOUS PROVISIONS OF THE ACT PRECLUDE STATE AGENCIES FROM DEVELOPING VIABLE DEMONSTRATION MODELS THAT DO NOT CONFORM TO THE PLANNING AND SERVICE AREA/AREA AGENCY SERVICE DELIVERY MODEL CURRENTLY REQUIRED BY THE ACT. IF THE ACT PROVIDED THE COMMISSIONER WITH THE AUTHORITY TO WAIVE SEVERAL OF THE CURRENT REQUIREMENTS THAT ARE ASSOCIATED WITH THE PLANNING AND SERVICE AREA/AREA AGENCY SERVICE DELIVERY MODEL, STATE AND AREA AGENCIES COULD BEGIN TO DEVELOP AND DEMONSTRATE COMMUNITY SERVICE SYSTEMS TO APPROPRIATELY SUSTAIN VULNERABLE OLDER PEOPLE IN THEIR COMMUNITIES AND IN THEIR HOMES.

FEES FOR SERVICES TO GENERATE NEW RESOURCES

THE BILL WOULD PERMIT STATES, AT THEIR OPTION, TO PERMIT AREA AGENCIES TO CHARGE FEES, BASED ON ABILITY TO PAY, FOR SUPPORTIVE SERVICES UNDER PART B OF TITLE III. THE STATE AGENCY WOULD BE REQUIRED TO ENSURE THAT NO FEES FOR SUCH SERVICES WERE CHARGED TO LOW INCOME INDIVIDUALS. IT WOULD BE LEFT TO STATE DISCRETION TO DETERMINE WHICH SUPPORTIVE SERVICES WOULD BE SUBJECT TO CHARGES, AS UNDER CURRENT LAW, THERE WOULD BE NO AUTHORITY TO CHARGE FEES FOR NUTRITION SERVICES UNDER PART C OF TITLE III.

THIS AMENDMENT WOULD HELP TO ENSURE THE MOST EFFECTIVE USE OF PROGRAM FUNDS, AS FEES COLLECTED FROM THOSE ABLE TO PAY WOULD ENABLE AREA AGENCIES TO EXPAND SERVICES AVAILABLE. AREA AGENCIES WOULD REMAIN FREE TO SEEK ONLY VOLUNTARY CONTRIBUTIONS; HOWEVER, THE PROPOSAL WOULD COMPLEMENT THAT AUTHORITY.
TRANSFER OF SUPPORTIVE AND NUTRITION SERVICES FUNDS


DURING THE REMAINDER OF FY 1987 AND INTO THE NEXT SEVERAL YEARS, THE ADMINISTRATION ON AGING IS EMBARKING UPON RENEWED AND MORE AGGRESSIVE EFFORTS TO SUPPORT STATE AND AREA AGENCIES ON AGING IN ASSISTING VULNERABLE AND FRAIL OLDER PERSONS AND THEIR FAMILIES TO FIND APPROPRIATE HELP TO MAINTAIN THEIR INDEPENDENCE WITHIN THEIR OWN COMMUNITIES FOR AS LONG AS POSSIBLE AND TO DELAY OR PREVENT UNNECESSARY INSTITUTIONALIZATION. THIS INCLUDES NOT ONLY NUTRITION SERVICES, BUT THE BROAD RANGE OF SUPPORTIVE SERVICES WHICH THESE OLDER PERSONS MAY REQUIRE.

THE AOA WILL CONTINUE TO PLACE EMPHASIS ON ACTIVITIES SUCH AS IN-HOME SERVICES AND TO SUPPORT STATE AND AREA AGENCIES ON AGING IN BUILDING A RESPONSIVE SYSTEM OF HOME-BASED CARE. IN THIS REGARD, WE WILL ALSO ASSIST STATE AND AREA AGENCIES TO BECOME MORE INVOLVED IN ASSISTING IN THE DEVELOPMENT OF QUALITY ASSURANCE STANDARDS IN THEIR STATES. WE BELIEVE SUCH STANDARDS ARE IMPORTANT AND NEEDED.

WHILE THE AOA BELIEVES THAT QUALITY ASSURANCE STANDARDS ARE IMPORTANT AND NEEDED, WE BELIEVE, HOWEVER, THAT SUCH STANDARDS MUST ADDRESS THE CIRCUMSTANCES OF INDIVIDUAL STATES AND COMMUNITIES AND CAN BEST BE DETERMINED BY EACH STATE IN ADDRESSING ITS SPECIAL NEEDS RELATED TO HOME CARE.

THIS ADMINISTRATION IS DEEPLY COMMITTED TO IMPROVING THE QUALITY OF LIFE THROUGH QUALITY SERVICES FOR ALL OF THIS NATION'S OLDER CITIZENS.

I WANT TO THANK YOU, SENATOR MELCHER, FOR THE OPPORTUNITY TO SHARE SOME OF THE IMPORTANT ACCOMPLISHMENTS OF THE OLDER AMERICANS ACT AND TO THANK YOU FOR YOUR SUPPORT OF PROGRAMS FOR OUR NATION'S ELDERLY CITIZENS AND THEIR FAMILIES. NOW, I WOULD BE HAPPY TO ANSWER YOUR QUESTIONS.
The CHAIRMAN. Thank you very much, Mr. Wells.

But I think you have heard this morning that the quality of life isn't very good for a lot of older Americans who are at home and need some health care. Do you think that you would recommend a broader, intensive use of the Older Americans Act for establishing some sort of mechanism, some sort of guideline, some sort of assurance that there is adequate home health care for older Americans?

Mr. WELLS. Well, Senator, we are already working to this end.

The CHAIRMAN. I have heard you say that. And since nothing much has been accomplished, I am just asking you for your recommendations. I don't know whether we should talk to you or talk to HCFA or talk to Secretary Bowen or talk to President Reagan or who we should talk to to find out what should be done. I thought I would start with you.

Mr. WELLS. Well, Senator, the State and area agencies on aging and the Administration on Aging—

The CHAIRMAN. Mr. Wells, I am going to have to interrupt here. I really appreciate what the States do in conjunction with the Older Americans Act. But we just don't have the time left today to hear how you are "working with States." I just want to start somewhere. Now, you are not going to tell me that you are going to start with 50 different States to establish who is in charge, are you?

Mr. WELLS. Senator, we have let a grant to develop quality in-home standards for use by State agencies on aging and area agencies on aging. The standards will be complete toward the end of this year. We intend to widely disseminate them. We are going to work with State agencies and help them implement them, at least in terms of Older Americans Act programs.

The CHAIRMAN. Would the standards tell us how to train people, or how to screen them or how to set up a system where you can call somebody if you're not getting any results?

Mr. WELLS. Senator, I am not fully aware of all the details of the proposal at this time. But my conversations with people who are familiar with the project indicate that it will be a very comprehensive set of standards that will go directly to the quality of the services and the impact on individuals who are receiving those services.

Again, we feel very strongly that such standards are important, and we are working to provide them.

The CHAIRMAN. And these standards would then lead to what?

Mr. WELLS. Well, we hope, Senator, that under the Older Americans Act, it will certainly result in improved in-home services provided by State and area agencies, and we hope that State agencies in their leadership role with other State—

The CHAIRMAN. Well, they say that your agency, it would be directly responsible to make sure that the people who provide the home health care are trained, they know what they're doing, and they're going out there to perform a service that is the proper, needed service.

Mr. WELLS. Senator, many of our State agencies right now have standards that they apply to activities delivered under the Older Americans Act. Performance-based contracting is an effort that we devoted some money to some years ago.
The CHAIRMAN. I think these are all terms, take "performance" for example—what was that?

Mr. WELLS. Performance-based contracting.

The CHAIRMAN. "Performance-based contracting."

Mr. WELLS. These are conditions that are—

The CHAIRMAN. And these are the conditions?

Mr. WELLS. These are conditions that our agencies place on the providers of services under the Older Americans Act.

The CHAIRMAN. Do you agree or disagree then with Ms. Lutton, who just testified, that for southwest Michigan there wasn't anybody in charge?

Mr. WELLS. Senator, I don't know about southwest Michigan.

The CHAIRMAN. Do you know about Michigan?

Mr. WELLS. We have area agencies on aging currently in place representing every community of the Nation. Of course, the quality of leadership varies amongst agencies and between States in the Nation. But these agencies are certainly charged with overall leadership on behalf of all matters as it relates to the elderly in their area.

The CHAIRMAN. Do you agree or disagree with Ms. Lutton, who said that there are no standards, that nobody is directly in charge?

Mr. WELLS. There may not be any standards in that community. We are working to fill that gap.

The CHAIRMAN. So the situation in southwest Michigan might be typical of the State of Michigan then?

Mr. WELLS. I couldn't say that, Senator.

The CHAIRMAN. Do you know of any State where it's different, any specific State where somebody is in charge?

Mr. WELLS. Yes, Senator. The State of Massachusetts.

The CHAIRMAN. The State of Massachusetts. Any others?

Mr. WELLS. The State of Rhode Island.

The CHAIRMAN. Well, that is two on the East Coast. If we progress from there, maybe we can get clear across the country.

Mr. WELLS. I know that the State of California sets very specific standards for services, social services delivered under various State programs.

The CHAIRMAN. Under various State programs.

Mr. WELLS. Yes, sir.

The CHAIRMAN. But now we're talking about Federal programs.

Mr. WELLS. But again, the Older Americans Act, the program for which we are responsible, is a State responsibility.

The CHAIRMAN. I don't think you are going to tell me, Mr. Wells, that the Administration on Aging is in charge of administering the Older Americans Act, unless we amended it or that you are in charge of Medicare or Medicaid, are you?

Mr. WELLS. Senator, neither the Administration on Aging nor State and area agencies are regulatory agencies.

The CHAIRMAN. Not regulatory.

Mr. WELLS. They are not compliance agencies. To do so would cut against the grain of the major leadership role and the advocacy role that State and area agencies must play across the board.

The CHAIRMAN. I understand that. So if we wait for your standards, I think what we are going to find is a broader view of the problem, not necessarily a solution to the problem. From the outset
when I started questioning you, Mr. Wells, I didn’t think the Administration on Aging under the statute, under any practice that you have had, has ever been the one to regulate, to force somebody to do what they’re supposed to do in order to get the job done. Isn’t that correct?

Mr. Wells. If I understand you, Senator, you are saying that State and area agencies are not meant to be regulatory agencies. The Chairman. Pardon me? What did you understand me to say?

Mr. Wells. That State and area agencies are not meant to be regulatory agencies, compliance agencies. The Chairman. No; I said Administration on Aging.

Mr. Wells. We also are not a regulatory agency. The Chairman. That’s right.

Mr. Wells. But we are undertaking very specific activities in this area to fill an important gap that exists. The Chairman. Shouldn’t we look just a little bit to your left, to HCFA, to give us some answers? Shouldn’t we?

Mr. Wells. Well, Senator, I can’t speak for the Health Care Financing Administration. The Chairman. We are going to let them speak for themselves. Mr. Hays?

STATEMENT OF LOUIS B. HAYS, ASSOCIATE ADMINISTRATOR FOR OPERATIONS, HEALTH CARE FINANCING ADMINISTRATION

Mr. Hays. Thank you, Mr. Chairman. I appreciate the opportunity to appear here today to speak about home health quality assurance.

As our administrator, Dr. Roper, stated several weeks ago when he appeared before this committee, we are committed to maintaining and enhancing a high level of quality throughout the Medicare and Medicaid programs.

Let me begin by briefly describing the Medicare and Medicaid home health benefits. To receive Medicare home health services, a beneficiary must be under a physician’s care, have a need for skilled care, and be homebound. When these conditions are met, patients can receive intermittent or part-time skilled nursing and nursing aide services, physical, speech, and occupational therapy, services of a medical social worker, and medical supplies and equipment. Medicare patients can also receive daily nursing care in their home for up to 3 weeks, and beyond in unusual circumstances if their physician certifies that the need for daily care will not continue indefinitely.

The home health benefit is one of the fastest-growing components of the Medicare program. Last year, almost 46 million home health visits were made to about 1.5 million beneficiaries. The number of home health agencies certified to provide care has almost doubled since 1980 to about 6,000 today. Since 1980 Medicare home health spending has tripled, to over $2.5 billion in fiscal year 1986.

The Medicaid home health benefit provides most of the same services as Medicare. In addition, a State can opt to provide personal care services to recipients in their homes. Since 1981 the Medicaid program has also permitted States to design innovative pro-
grams for providing home- and community-based services to target-
ed groups of recipients who would otherwise be in nursing homes. In 1985, the latest year for which data are available, the Medicaid program served over half a million recipients in their homes at a cost of approximately $1.1 billion.

To qualify as a provider of care for Medicare and Medicaid pa-
tients, a home health agency must meet specific requirements or conditions of participation to ensure the health and safety of indi-
viduals receiving services in their homes. The conditions cover per-
sonnel and administrative requirements and requirements address-
ing the provision of specific types of care.

Let me be more specific about the personnel qualifications, which I know are of particular concern to this committee. Professional personnel are required to meet specific educational, licensure, and experience standards and are required to perform specific duties. For example, a registered nurse must be a graduate of an approved school of professional nursing and be licensed as a registered nurse by the State. All home health nursing care must be provided under the supervision of a registered nurse and must be in accord with a plan of treatment developed for each patient and reviewed periodi-
cally.

Our regulations require that home health aides be trained and closely supervised to assure their competence in providing care.

Let me note at this point that we are extremely concerned that a provision of the Omnibus Reconciliation Act of 1980 has not been implemented. This provision calls for home health aide services to be provided by aides who have successfully completed a training program approved by the Secretary of Health and Human Services. We have recently become aware of the situation and have taken steps to publish a regulation as soon as possible.

We determine whether home health agencies meet our require-
ments on the basis of surveys performed by State agencies. These surveys include visits to patients in their homes. We are working to focus our home health surveys more on patients and less on paperwork, similar to what we have done for our skilled nursing fa-
cilities.

We are now developing a patient outcome-oriented survey instru-
ment which will enable us to assess even more effectively the qual-
ity of care provided in the home. We will implement an outcome-

We have increased our home health agency budget for fiscal year 1988 by 48 percent to significantly increase the frequency of sur-
veys and home visits.

We also rely on other mechanisms to review care being provided by home health agencies. The medical review program assures that payment is made only for those services that were medically neces-
sary and appropriate.

Under the coverage compliance review program, fiscal interme-
diaries visit all newly qualifying home health agencies and a sample of patients' homes to assure that care is being provided in accordance with Medicare program requirements. A concurrent au-
thorization program which we will pilot test beginning in June will reduce denials by paying for bills consistent with plans of treat-
ment that have been previously approved by our fiscal intermediary.

Finally, we will be working with the Pennsylvania peer review organization to pilot test the protocol for review of the quality of care provided in home settings that will be required for all peer review organizations. This review will be performed in conjunction with review of readmissions to hospitals occurring within 31 days of discharge.

Peer review organizations will also be implementing by August a system to review and respond to beneficiaries' complaints about quality.

In conclusion, Mr. Chairman, let me assure you that Dr. Roper and the 3,800 men and women of the Health Care Financing Administration do care. Our existing mechanisms and those under development demonstrate that our care and concern are a reality, not rhetoric.

Thank you very much, and I would be very pleased to answer any questions that you might have.

[The prepared statement of Mr. Hays follows:]
MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE, I APPRECIATE THE OPPORTUNITY TO APPEAR HERE TODAY TO SPEAK ABOUT HOME HEALTH QUALITY ASSURANCE. AS DR. ROPER STATED SEVERAL WEEKS AGO WHEN HE APPEARED BEFORE THIS COMMITTEE, THIS ADMINISTRATION IS COMMITTED TO MAINTAINING AND ENHANCING A HIGH LEVEL OF QUALITY THROUGHOUT THE MEDICARE AND MEDICAID PROGRAMS. I CAN ASSURE YOU THAT OUR COMMITMENT EXTENDS TO CARE PROVIDED IN ALL SETTINGS, INCLUDING OUR BENEFICIARIES' HOMES.

CHANGES OVER THE PAST FEW YEARS IN HOW AND WHERE SERVICES ARE DELIVERED HAVE FOCUSED ATTENTION ON CARE PROVIDED IN OUTPATIENT SETTINGS. BECAUSE OF THIS CHANGING EMPHASIS, WE ARE REASSESSING EXISTING ACTIVITIES AND EXPLORING NEW POSSIBILITIES TO ASSURE THAT QUALITY OF CARE PROVIDED IN HOMES AND OTHER OUTPATIENT SETTINGS MEETS THE HIGH STANDARDS OUR BENEFICIARIES HAVE COME TO EXPECT.

BACKGROUND

LET ME BEGIN BY BRIEFLY DESCRIBING THE MEDICARE AND MEDICAID HOME HEALTH BENEFITS WHICH ARE AIMED AT VERY DIFFERENT TYPES OF PATIENTS — MEDICARE BEING PRIMARILY FOR POST-ACUTE PATIENTS AND MEDICAID GENERALLY FOR PATIENTS WITH LONGER-TERM, CHRONIC CONDITIONS.
WE VIEW THE MEDICARE HOME HEALTH BENEFIT AS AN ESSENTIAL COMPONENT OF THE MEDICARE BENEFIT PACKAGE. HOME HEALTH CARE IS OFTEN THE FINAL STAGE OF A PATIENT'S RECOVERY PROCESS FROM AN ACUTE ILLNESS -- A PERIOD WHERE THE PATIENT STILL REQUIRES SOME SKILLED CARE BUT GENERALLY NOT ON A DAILY BASIS. TO RECEIVE MEDICARE HOME HEALTH SERVICES, A BENEFICIARY MUST BE UNDER A PHYSICIAN'S CARE, HAVE A NEED FOR SKILLED CARE AND BE HOMEBOUND. WHEN THESE CONDITIONS ARE MET, PATIENTS CAN RECEIVE INTERMITTENT OR PART-TIME SKILLED NURSING AND NURSING AIDE SERVICES, PHYSICAL, SPEECH AND OCCUPATIONAL THERAPY, THE SERVICES OF A MEDICAL SOCIAL WORKER, AND MEDICAL SUPPLIES AND EQUIPMENT. MEDICARE PATIENTS CAN ALSO RECEIVE DAILY NURSING CARE IN THEIR HOME FOR UP TO 3 WEEKS, AND BEYOND IN UNUSUAL CIRCUMSTANCES, IF THEIR PHYSICIAN CERTIFIES THAT THE NEED FOR DAILY CARE WILL NOT CONTINUE INDEFINITELY.

THE HOME HEALTH BENEFIT IS ONE OF THE FASTEST GROWING COMPONENTS OF THE MEDICARE PROGRAM AND MORE MEDICARE BENEFICIARIES ARE RECEIVING HOME CARE THAN EVER BEFORE. LAST YEAR, ALMOST 46 MILLION HOME HEALTH VISITS WERE MADE TO ABOUT 1.5 MILLION BENEFICIARIES. THE NUMBER OF HOME HEALTH AGENCIES CERTIFIED TO PROVIDE CARE HAS ALMOST DOUBLED SINCE 1980 TO ABOUT 6,000 TODAY. SINCE 1980, MEDICARE HOME HEALTH SPENDING HAS TRIpled TO OVER $2.5 BILLION IN FY 1986.

THE MEDICAID HOME HEALTH BENEFIT PROVIDES MOST OF THE SAME SERVICES AS MEDICARE. IN ADDITION, A STATE CAN OPT TO PROVIDE PERSONAL CARE SERVICES TO RECIPIENTS IN THEIR HOMES, A BENEFIT GEARED TO INDIVIDUALS WITH FEWER MEDICAL NEEDS THAN HOME HEALTH PATIENTS BUT WHO NEED SOME ASSISTANCE TO REMAIN IN THE HOME. BECAUSE OF THIS FEATURE, THE MEDICAID HOME CARE BENEFIT IS GENERALLY SEEN AS A LONG TERM CARE BENEFIT, AS OPPOSED TO THE MEDICARE BENEFIT WHICH IS MOST FREQUENTLY USED AS A POST-ACUTE, SHORTER-TERM BENEFIT.

MEDICAID SERVICES PROVIDED IN THE HOME HAVE MADE IMPORTANT CONTRIBUTIONS TO OUR SENIOR CITIZENS. IN PARTICULAR, SINCE 1981 THE MEDICAID PROGRAM HAS PROVIDED STATES WITH A MECHANISM WHICH ALLOWS THEM TO PROVIDE HOME AND COMMUNITY-BASED SERVICES TO TARGETED GROUPS OF RECIPIENTS. STATES HAVE BEEN ABLE TO DESIGN INNOVATIVE AND COST-EFFECTIVE WAYS TO ASSIST MANY ELDERLY
MEDICAID RECIPIENTS, WHO WOULD OTHERWISE BE IN NURSING HOMES, TO REMAIN IN THEIR HOMES. THE TYPES OF SERVICES PROVIDED UNDER THESE PROGRAMS INCLUDE RESPITE CARE, THE PROVISION OF MEALS, AND CASE MANAGEMENT SERVICES NOT OTHERWISE COVERED BY MEDICAID. IN 1985, THE LATEST YEAR FOR WHICH DATA IS AVAILABLE, THE MEDICAID PROGRAM SERVED OVER HALF A MILLION RECIPIENTS IN THEIR HOMES AT A COST OF APPROXIMATELY $1.1 BILLION.

ASSURING QUALITY

THE DRAMATIC GROWTH IN THE USE OF HOME HEALTH SERVICES REPRESENTS A TRENDS THAT WILL PROBABLY CONTINUE, GIVEN THE CURRENT EMphasis ON EFFICIENT USE OF HOSPITAL RESOURCES AND THE INCREASED MEDICAL AND SOCIAL EMPHASIS ON THE PROVISION OF CARE IN NONINSTITUTIONAL SETTINGS. JUST AS WE HAVE MOVEd AGGRESSIVELY TO ASSURE THE QUALITY OF CARE PROVIDED TO PATIENTS IN HOSPITALS, WE ARE ALSO STRENGTHENING AND IMPROVING OUR PROCEDURES FOR ASSURING QUALITY CARE IN OUTPATIENT SETTINGS, INCLUDING HOME CARE.

SURVEY AND CERTIFICATION

TO QUALIFY AS A PROVIDER OF CARE FOR MEDICARE AND MEDICAID PATIENTS, A HOME HEALTH AGENCY MUST MEET SPECIFIC REQUIREMENTS, OR CONDITIONS OF PARTICIPATION. THESE CONDITIONS WERE DEVELOPED IN COOPERATION WITH PROFESSIONAL ORGANIZATIONS AND PRESCRIBE SPECIFIC REQUIREMENTS NECESSARY TO ENSURE THE HEALTH AND SAFETY OF INDIVIDUALS RECEIVING SERVICES IN THEIR HOMES. THE CONDITIONS COVER THREE BROAD AREAS: PERSONNEL REQUIREMENTS FOR THOSE GIVING CARE, ADMINISTRATIVE REQUIREMENTS FOR AN AGENCY TO EFFECTIVELY RENDER CARE, AND REQUIREMENTS WHICH ADDRESS THE PROVISION OF SPECIFIC TYPES OF CARE.

LET ME BE MORE SPECIFIC ABOUT THE PERSONNEL QUALIFICATIONS, WHICH I KNOW ARE OF PARTICULAR CONCERN TO THIS COMMITTEE. PROFESSIONAL PERSONNEL ARE REQUIRED TO MEET SPECIFIC EDUCATIONAL, LICENSURE AND EXPERIENCE STANDARDS AND ARE REQUIRED TO PERFORM SPECIFIC DUTIES. FOR EXAMPLE, A REGISTERED NURSE MUST BE A GRADUATE OF AN APPROVED SCHOOL OF PROFESSIONAL NURSING AND BE LICENSED AS A REGISTERED NURSE BY THE STATE.

ALL HOME HEALTH NURSING CARE MUST BE PROVIDED UNDER THE SUPERVISION OF A REGISTERED NURSE AND MUST BE IN ACCORD WITH A
PLAN OF TREATMENT DEVELOPED FOR EACH PATIENT AND REVIEWED PERIODICALLY. OUR REGULATIONS REQUIRE THAT HOME HEALTH AIDES BE CLOSELY SUPERVISED TO ASSURE THEIR COMPETENCE IN PROVIDING CARE. AIDES MUST ALSO BE CAREFULLY TRAINED IN METHODS OF ASSISTING PATIENTS TO ACHIEVE MAXIMUM SELF-RELIANCE, IN PRINCIPLES OF NUTRITION, IN THE AGING PROCESS AND IN PROCEDURES FOR MAINTAINING A CLEAN, HEALTHFUL AND PLEASANT ENVIRONMENT, AMONG OTHER RESPONSIBILITIES SPECIFIED IN REGULATIONS.

LET ME NOTE, AT THIS POINT, THAT WE ARE EXTREMELY CONCERNED THAT A PROVISION OF THE OMNIBUS RECONCILIATION ACT OF 1980 HAS NOT BEEN IMPLEMENTED. THIS PROVISION CALLS FOR HOME HEALTH AIDE SERVICES TO BE PROVIDED BY AIDES WHO HAVE "SUCCESSFULLY COMPLETED A TRAINING PROGRAM APPROVED BY THE SECRETARY." WE HAVE RECENTLY BECOME AWARE OF THIS SITUATION AND HAVE TAKEN STEPS TO PUBLISH A PROPOSED REGULATION AS SOON AS POSSIBLE.

WE DETERMINE WHETHER HOME HEALTH AGENCIES MEET THE REQUIREMENTS TO PROVIDE SERVICES TO MEDICARE AND MEDICAID PATIENTS BASED ON SURVEYS PERFORMED BY STATE AGENCIES, USUALLY STATE HEALTH DEPARTMENTS. WE SUPERVISE THE SURVEY PROCESS CENTRALLY AND ISSUE NATIONAL GUIDELINES TO ASSIST SURVEYORS IN APPLYING THE CONDITIONS OF PARTICIPATION TO HOME HEALTH AGENCIES. WE ALSO CONDUCT REGULAR TRAINING OF SURVEYORS TO PROMOTE CORRECT AND CONSISTENT SURVEY FINDINGS.

VISITS TO PATIENTS IN THEIR HOMES IS ONE ASPECT OF OUR CURRENT SURVEY PROCESS WHICH IS INTENDED TO IDENTIFY QUALITY PROBLEMS. WE ARE WORKING TO FOCUS OUR HOME HEALTH SURVEYS MORE ON PATIENTS AND LESS ON DOCUMENTATION AND PAPERWORK. WE HAVE ALREADY IMPLEMENTED NEW SURVEY PROCEDURES FOR NURSING HOMES THAT EMPHASIZE DIRECT OBSERVATION OF PATIENT CARE AND WE WANT TO EXTEND THIS TYPE OF SURVEY TO HOME HEALTH AGENCIES. TO THIS END, WE ARE NOW DEVELOPING, UNDER CONTRACT, A PATIENT OUTCOME ORIENTED SURVEY INSTRUMENT WHICH WILL ENABLE US TO ASSESS MORE EFFECTIVELY THE ACTUAL QUALITY OF CARE PROVIDED IN THE HOME. WE EXPECT TO IMPLEMENT AN OUTCOME ORIENTED SURVEY OF HOME HEALTH AGENCIES IN FY 1988.
WHEN STATE AGENCIES IDENTIFY DEFICIENCIES IN HOME HEALTH AGENCY PERFORMANCE, THEY MONITOR HOME HEALTH AGENCIES' EFFORTS TO IMPROVE THEIR OPERATIONS. OUR EMPHASIS IS ON ADVISING HOME HEALTH AGENCIES ABOUT NECESSARY CORRECTIONS AND GIVING THEM AN OPPORTUNITY TO COME UP TO STANDARDS. HOWEVER, IF DEFICIENCIES ARE NOT CORRECTED OVER TIME, STATE AGENCIES WILL RECOMMEND TERMINATION FROM PARTICIPATING IN MEDICARE AND MEDICAID. THESE PROCEDURES HAVE RECENTLY BEEN STRENGTHENED, PARTICULARLY WHERE THE HEALTH AND SAFETY OF PATIENTS ARE SERIOUSLY THREATENED.

THE SURVEY AND CERTIFICATION PROCESS IS AN IMPORTANT Cornerstone OF OUR QUALITY ASSURANCE PROGRAM AND WILL CONTINUE TO HAVE OUR STRONG SUPPORT. AS EVIDENCE OF OUR BELIEF IN THE EFFECTIVENESS OF THIS PROCESS, WE HAVE INCREASED OUR HOME HEALTH AGENCY SURVEY BUDGET FOR FY 1986 BY 48 PERCENT TO SIGNIFICANTLY INCREASE THE FREQUENCY OF SURVEYS. OVER $3 MILLION OF ADDITIONAL FUNDS WILL BE DESIGNATED SPECIFICALLY FOR HOME HEALTH AGENCY SURVEYS. WE BELIEVE THIS CLEARLY DEMONSTRATES OUR COMMITMENT TO QUALITY.

MEDICAL AND COVERAGE COMPLIANCE REVIEW

WE ALSO Rely ON OTHER MECHANISMS TO ASSURE THAT ONLY NECESSARY CARE IS BEING PROVIDED BY HOME HEALTH AGENCIES. UNDER THE MEDICAL REVIEW PROGRAM, A SAMPLE OF MEDICARE CLAIMS SUBMITTED TO INTERMEDIARIES FOR PAYMENT IS REVIEWED BY NURSES OR PHYSICIANS TO DETERMINE IF THE SERVICES WERE MEDICALLY NECESSARY AND APPROPRIATE. THIS PROCEDURE HAS RECENTLY BEEN FACILITATED THROUGH THE USE OF NEW FORMS WHICH PROVIDE MORE AND BETTER INFORMATION FOR REVIEWERS TO MAKE ACCURATE DECISIONS. WE ARE WORKING, WITH THE INPUT OF HOME HEALTH AGENCIES AND INDUSTRY REPRESENTATIVES, TO SIMPLIFY AND IMPROVE THESE FORMS. IN ADDITION, CONSISTENCY OF INTERMEDIARY DECISIONS HAS BEEN GREATLY IMPROVED THROUGH THE RECENT MOVE FROM 48 INTERMEDIARIES TO 10 REGIONAL INTERMEDIARIES.

UNDER THE COVERAGE COMPLIANCE REVIEW PROGRAM, FISCAL INTERMEDIARIES VISIT ALL NEWLY QUALIFYING HOME HEALTH AGENCIES AND, ON A RANDOM BASIS, PATIENTS' HOMES TO ASSURE THAT CARE IS BEING PROVIDED IN ACCORDANCE WITH MEDICARE PROGRAM STANDARDS AND REQUIREMENTS.
CONCURRENT AUTHORIZATION

In June we will implement a pilot program of concurrent authorization for home health services. Under this initiative, home health agencies will submit patient plans of care to intermediaries which will decide, within 5 working days, whether the proposed care meets medical necessity and coverage requirements. The intermediary will then pay claims that are consistent with the plan of treatment, thereby reducing the risk of denials. This program is expected to provide financial protection to both the home health patient and agency providing care. The pilot will be conducted at two sites for a 90-day period after which we will evaluate the program.

PRO REVIEW

Finally, we will shortly be working with peer review organizations (PROs) to review care provided in home settings. The Omnibus Reconciliation Act of 1986 (OBRA) required that PROs review post-hospital care provided in various settings, including care provided by home health agencies. PROs will also be required to review readmissions to hospitals occurring within 31 days of discharge. In reviewing readmissions, PROs will look at intervening care, including services provided by home health agencies, to identify problems with quality.

These provisions become effective for PRO contracts entered into after January 1, 1987. The first contract to be affected will be that of the Pennsylvania PRO which is scheduled for renewal or award in July of this year. Since the Pennsylvania PRO is out-of-phase with other PRO contracts, early implementation of the new requirement through this PRO will provide us with an excellent opportunity to use Pennsylvania as a pilot in testing a protocol for this review.

We are also developing a protocol for PROs to establish systems to review and respond to beneficiary complaints about quality, as required by OBRA. PRO contracts will be modified so that the complaint system will be operational by August.
RESEARCH

I WOULD LIKE TO BRIEFLY DESCRIBE OUR RESEARCH AND DEMONSTRATION PROJECTS WHICH ADDRESS HOME HEALTH QUALITY. WE NOW HAVE UNDERWAY IN WASHINGTON AND COLORADO SMALL PILOT PROJECTS ON THE DEVELOPMENT AND TESTING OF QUALITY OUTCOME MEASUREMENTS FOR HOME HEALTH CARE. IN COLORADO, WE WILL ALSO BE COMPARING THE COST, QUALITY AND EFFECTIVENESS OF CARE PROVIDED BY FREESTANDING AND HOSPITAL-BASED HOME HEALTH AGENCIES, AND EXAMINING THE IMPACT OF THE HOSPITAL PROSPECTIVE PAYMENT SYSTEM ON THE QUALITY OF HOME HEALTH SERVICES. WE ARE ALSO SUPPORTING TWO PROJECTS TO REVIEW THE ADEQUACY AND OUTCOMES OF POST-HOSPITAL, OR AFTERCARE, SERVICES. ALSO, BY THE END OF THE YEAR WE EXPECT TO HAVE INITIATED A STUDY AND DEMONSTRATION FOCUSING ON OUTCOME-ORIENTED QUALITY ASSESSMENT FOR HOME HEALTH SERVICES.

WE EXPECT THESE STUDIES WILL PROVIDE US WITH INFORMATION IN THE FUTURE TO DEFINE AND IMPROVE OUR OUTCOME ORIENTED SURVEY PROCESS AND TO ASSIST US IN MONITORING THE QUALITY OF HOME HEALTH CARE.

CONCLUSION

WE BELIEVE THAT THE EXISTING MECHANISMS WE HAVE IN PLACE AND THE NEW MECHANISMS UNDER DEVELOPMENT UNDERLINE OUR CONTINUING COMMITMENT TO QUALITY OF CARE FOR OUR BENEFICIARIES. WE KNOW THAT IMPROVEMENTS CAN ALWAYS BE MADE, AND WE BELIEVE OUR ACTIVITIES DEMONSTRATE A SINCERE INTEREST IN MOVING FORWARD IN OUR QUALITY ASSURANCE EFFORTS.

I WOULD BE PLEASED TO ANSWER YOUR QUESTIONS.
The CHAIRMAN. Mr. Hays, you have sort of given us the framework of how you spend $3.5 billion for home health care, or perhaps a little bit more, maybe $4 billion per year through Medicare and Medicaid. Is that correct?

Mr. HAYS. Yes.

The CHAIRMAN. I assume that you have heard a lot of the testimony this morning, have you not?

Mr. HAYS. I have heard part of it, not all of it.

The CHAIRMAN. Not all of it. But the testimony has been of the nature that people receiving home health care—and this is a broad variety of payments through either Medicare, insurance or States or private funds. But the one thing that has been uniform in the testimony we have heard, is that whoever provides these nurses or health aides for the patients at home doesn’t have any process of screening or skills assessment. It’s obvious from the testimony, that there should be a test to see if the aides can operate medical equipment or even do minimal things like checking temperature.

Why don’t you have in place something that would require some sort of a framework, some test, some—I hate to use the word “guidelines” because it ought to be a lot stiffer than that—some requirements, that go beyond merely drawing up a regulation? Why in fact don’t you have a regulation drawn and in force and in effect that would set up what type of training, what type of qualifications these people should have before they go out to the home?

Mr. HAYS. Mr. Chairman, our existing regulations do require that the staff of the home health agencies be trained.

The CHAIRMAN. Trained for what? Now, you used the word, a general term. Trained for what?

Mr. HAYS. If I could finish that, Mr. Chairman. The regulation that I mentioned which we are now putting into place would go beyond that to require that the training be in accordance with the—

The CHAIRMAN. Now, wait a minute. Tell me what you have now. Tell me what you have now. You used the term, I didn’t. You said the regulation required that they be trained. I am saying: trained for what?

Mr. HAYS. I would like to ask Mr. Bob Wren, who is the director of our office of coverage policy, and is more intimately familiar with the existing—

The CHAIRMAN. Oh, well, before—

Mr. HAYS [continuing]. The existing regulations that are on the books and that we do enforce to address that question, Mr. Chairman.

The CHAIRMAN. Now, before I get through with you, Mr. Hays, let me ask you what you know about it, because you have had plenty of time to know about it. What was the bill you mentioned, Reconciliation Act of 1980?

Mr. HAYS. Yes.
The CHAIRMAN. Did it not require that regulations be drafted?
Mr. HAYS. Yes.
The CHAIRMAN. To cover specific regulations for training programs?
Mr. HAYS. It said that we were to have training standards prescribed by the Secretary for the home health——
The CHAIRMAN. Training standards.
Mr. HAYS. The home health aide would have to have training in accordance with standards specified by the Secretary. The statute left discretion to us as to what those standards would be.
The CHAIRMAN. In other words, the law said, "Mr. Secretary, draw up some standards to say what these aides should be able to do." And that was in 1980, and you don't have them now, do you, as of this moment in time?
Mr. HAYS. We were, shall we say, stunned to discover that those regulations had not been implemented.
The CHAIRMAN. You were stunned to discover that they hadn't been drafted, that you didn't have them in place?
Mr. HAYS. That's correct.
The CHAIRMAN. And $4 billion, not to mention what else goes through, the insurance programs and private and State funds.
Mr. HAYS. Those standards would not address anything other than Medicare and Medicaid, Mr. Chairman, as I understand it.
The CHAIRMAN. That would address only the $4.5 billion?
Mr. HAYS. I can assure you, as I testified, we have a vigorous program, of which we are very proud, that reviews through our survey and certification agencies, our fiscal intermediaries, and increasingly through our peer review organizations, the quality of care provided by home health agencies.
The CHAIRMAN. You review it, and you haven't drafted the regulations to even tell them what they're supposed to do? What do you review?
Mr. HAYS. We review against all of the conditions of participation. We look at the——
The CHAIRMAN. Well, isn't that a review to see how they fill out the paperwork and send it in so they can collect their money?
Mr. HAYS. Certainly that is part of it.
The CHAIRMAN. That's part of it.
Mr. HAYS. But that is not what I am referring to.
The CHAIRMAN. Is that a big part of it?
Mr. HAYS. It is a big part of it. For example——
The CHAIRMAN. Mr. Hays, I don't think that means much to the patient.
Mr. HAYS. That is why we make thousands of home visits. That is why the physician is required to sign a plan of treatment. That is why this is all under the supervision of a physician and then under the supervision of a registered nurse. This is not just a willy-nilly program in which anything can happen to people out there. We realize, as has been brought out here this morning, abuses can occur. Fortunately, those are a small number of cases. Obviously, even one case of abuse is one case too many, but that is why we are stepping up our budget for these surveys by 50 percent this year.
The CHAIRMAN. Mr. Hays, I don't want to be unfair to you or any one individual, but we have heard repeated testimony today that it wasn't just one instance, that it was several instances.

One patient mentioned that over the same time frame that you are talking about between 1980 and today, 7 years when regulations were supposed to be in place—we heard one witness testify that they had bad experiences with over a half a dozen different people sent by one agency. Every witness has told us that this happened repeatedly over a period of years.

The witness before you people said she had been working for different home care agencies and it wasn't just a regrettable incident or two, it was a continuous, ongoing experience.

We have asked everybody, "Who should be in charge?" Who should be in charge?

Mr. HAYS. The physician who approves the plan of treatment and the registered nurse who supervises the provision of the treatment, and to the extent that Medicare is involved, the Health Care Financing Administration through our survey and certification agencies, through our fiscal intermediaries, and through the peer review organizations.

The CHAIRMAN. Well, I am afraid those kinds of answers, Mr. Hays, aren't acceptable. Who should be in charge? Now, is the Federal Government going to be in charge? Are you going to draft a regulation that sets qualifications for Medicare and Medicaid payments for home health care, and what they have to do to meet the patients' needs?

Mr. HAYS. Mr. Chairman, the regulation that you are referring to goes to one narrow part of the entire home health picture. We have in place—

The CHAIRMAN. It happens to be that one so called "narrow part" that we are very interested in today. We think it's a pretty broad part that may affect as many as 5 million Americans. Now, that is a pretty big problem.

Mr. HAYS. I don't want to intentionally give the erroneous impression, though, that we do not have regulations in place governing the home health benefit, because we do, and those regulations in turn form the whole framework for inspecting home health and the quality of home health care that is provided to our 1.5 million Medicare beneficiaries who received home health services last year.

The CHAIRMAN. I am sure, Mr. Hays, that you want to set the record straight here, make it less confusing and answer the questions honestly. You have already said you agree the 1980 Reconciliation Act required that regulations be drafted to set the standards for home health care for patients. We are in synchronization that far.

Mr. HAYS. The home health aide training, Mr. Chairman.

The CHAIRMAN. Pardon me?

Mr. HAYS. Those regulations are directed at home health aides.

The CHAIRMAN. And nurses?

Mr. HAYS. It's my understanding that those are only with respect to home health aides.

The CHAIRMAN. Not to nurses?

Mr. HAYS. That's correct.

The CHAIRMAN. Do you have regulations on nurses?
Mr. HAYS. Yes, as we do for all employees of home health agencies who provide any sort of care to—

The CHAIRMAN. Do you have regulations on nurses that say that when a nurse is sent out that has never operated essential equipment that that nurse shouldn't be sent out?

Mr. HAYS. It's my understanding that the—

The CHAIRMAN. And therefore there shouldn't be any payment?

Mr. HAYS. It's my understanding that the regulations require that the personnel be trained and are able to provide the type of service that they in fact are providing.

The CHAIRMAN. You haven't identified what type of training that is, though, have you, or what experience that is?

Mr. HAYS. As I recall, the regulations require that training be provided and that it be appropriate training. The regulations do not spell out the specific type of training that is to be provided.

The CHAIRMAN. I am sure, then, that you have read the inspector general's report on this very topic?

Mr. HAYS. I have seen that, yes.

The CHAIRMAN. You have seen that. Do you agree with it?

Mr. HAYS. As I testified, the regulations require that training be provided and that it be appropriate training. The regulations do not spell out the specific type of training that is to be provided.

The CHAIRMAN. Which you do not have now.

Mr. HAYS. Not with respect to the specific requirements of the statute that we referred to previously.

The CHAIRMAN. Would you agree with this paragraph directly out of the inspector general's report:

Legislative changes in section 1861(m)(4) of the Social Security Act in 1981 required home health aides to have successfully completed a training program approved by the Secretary. HCFA drafted a regulation which established a training curriculum to meet the intent of the law, and that regulation was never finalized and no training standard was established.

Do you agree with that?

Mr. HAYS. As I testified, that is the fact, and we are putting that regulation in place.

The CHAIRMAN. That is a very specific regulation and you are testifying that you were shocked to learn that it hadn't been implemented?

Mr. HAYS. Yes.

The CHAIRMAN. All right. Now, do you think this is a Federal responsibility and HCFA's responsibility not only to draft the regulation but to carry it out and enforce it?

Mr. HAYS. Certainly.

The CHAIRMAN. When could it be done?

Mr. HAYS. We will have a proposed regulation published as soon as possible. That probably means within the next couple of months.

The CHAIRMAN. Within the couple of months, and it will start through the Federal Register for—

Mr. HAYS. Public comment.

The CHAIRMAN. [continuing]. Public comment, and so therefore it might be in place prior to the end of the year?
Mr. Hays. I would certainly hope so.
The Chairman. You would hope so.
All right. Now, is there anything else you would like to tell me about this? Shouldn’t this be a Federal responsibility. If it is a Federal responsibility will it sort of set standards for everybody else, all of these agencies that use Medicare and Medicaid?
Mr. Hays. Are you referring again specifically to the training standards?
The Chairman. Yes.
Mr. Hays. I would assume, as a practical matter, that would ultimately be the result. To the extent that the home health agency wishes to participate in Medicare and Medicaid, they would have to follow those standards. I assume that the majority of home health agencies want to participate in Medicare and Medicaid.
The Chairman. Isn’t it true that more than 95 percent of them participate in Medicare and Medicaid now?
Mr. Hays. I don’t know that statistic, but I wouldn’t be at all surprised. That sounds right.
The Chairman. That statement is not an off-the-wall statement. It is probably an accurate statement. So therefore, your standards that are imposed by the regulations will probably cover at least that many agencies.
Mr. Hays. Well, that assumes that they all can comply with that requirement and can continue to participate in Medicare and Medicaid.
The Chairman. Is it your purpose that these regulations be dominant, not just for the agencies? How are you going to enforce them; by yourselves or through the States?
Mr. Hays. Yes, is the answer. We enforce them, but as is the case with survey and certification in general, that is done primarily through the State agencies that we have working for us by statute under contract. Then we do a certain number of direct Federal surveys using Federal staff to make sure that the State agencies are complying with our requirements.
The bottom line is, yes, we do enforce them.
The Chairman. Who is going to recommend termination of an agency that doesn’t comply?
Mr. Hays. The recommendation for termination is made by the State survey and certification agency, and then we act on that recommendation.
The Chairman. Does it work?
Mr. Hays. Yes.
The Chairman. Have you terminated any?
Mr. Hays. Yes.
The Chairman. How many?
Mr. Hays. Well, last year we had 12 involuntary terminations, which were outright Federal terminations. We had several hundred so-called voluntary terminations.
The Chairman. Well, 12, you called them “involuntary,” meaning you told them they’re out of business with Medicare and Medicaid.
Mr. Hays. Yes.
The Chairman. How many were recommended?
Mr. HAYS. I don't know the answer to that; if there is a difference between the two numbers—in any event, I will be happy to supply that information for the record.

The CHAIRMAN. Does either one of your cohorts know how many were recommended?

Mr. HAYS. No, I'm sorry, we don't know the answer to that question but I will provide that information.

[Subsequent to the hearing, the following was submitted by Mr. Hays for the hearing record:]

We do not keep data on the number of those providers, in jeopardy of termination, which are working to correct deficiencies. Our first knowledge of a potential termination is when it is recommended by the State agency, and we concur in virtually all State agency recommendations.

The CHAIRMAN. All right. But several hundred just disappeared on their own?

Mr. HAYS. Well, several hundred so-called voluntary terminations, which could range from anything from a corporate merger of two existing home health agencies to a situation where the agency decided on its own that it couldn't meet our requirements and decided to get out of the program.

The CHAIRMAN. Yes. Then you would agree, I take it, Mr. Hays, that regulations setting up the standards, regulations setting up the requirements of training, must be in place and that it is HCFA's responsibility to do so?

Mr. HAYS. It is certainly our responsibility to get the regulation implemented that flows from that 1980 statute, yes.

The CHAIRMAN. Now, I just want to be sure now. Your interpretation of what the 1980 law requires is that there will be, there must be training standards and standards qualifications?

Mr. HAYS. Essentially, yes. Certainly, a training program that meets the requirements of the Secretary, yes.

The CHAIRMAN. That meets the requirements of the Secretary?

Mr. HAYS. Yes.

The CHAIRMAN. All right. Thank you very much.

Mr. HAYS. Thank you.

The CHAIRMAN. And you, too, Mr. Wells. Thank you all.

Mr. WELLS. Thank you, Senator.

The CHAIRMAN. The committee will be in recess until 2:15.

[Whereupon, at 12:45 p.m., the committee was recessed, to reconvene at 2:15 p.m., this same day.]

AFTERNOON SESSION

The CHAIRMAN. The committee will come to order.

Our next witness will be Mr. Donald Nicholson, Assistant Inspector General.

Mr. Nicholson?

STATEMENT OF DONALD NICHOLSON, ASSISTANT INSPECTOR GENERAL, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. NICHOLSON. Thank you, Mr. CHAIRMAN. It is a pleasure to be here this afternoon. As you pointed out, I am Assistant Inspector General. My specific title is Assistant Inspector General for Analysis and Inspections in the Department of Health and Human Serv-
ices, and I am here today at the request of the committee to present to the members the findings of a draft report that we recently released entitled "Home Health Aide Services for Medicare Patients." 2

The Office of the Inspector General produces many reports. Many of these reports are investigative and audit type reports. We also produce what we call inspection reports, which for lack of a better word are evaluative studies. We do these studies after we do literature search and talk to people that we consider to be professionals and experts in the field. And after having done that and backing off and taking a look at the information that we have garnered, if we feel that there is a potential for a problem, then we will conduct an inspection. We felt that there was a potential for a problem in the area of home health aide services, thus our reason for us having conducted that inspection.

I am going to skip over the first couple or three pages of my written testimony because it represents introductory remarks and discusses some of the same information that Mr. Hays has already provided for the committee, and go immediately into the inspection itself and why it was that we did it and what it was that we found.

Our inspection was designed to look at the type and number of services provided to Medicare beneficiaries by home health aides and the training and the supervision of the aides who are required to perform these services. Our study included onsite visits in seven States: California, Illinois, Connecticut, New York, Pennsylvania, Tennessee, and Texas. We went into 16 selected Medicare certified home health care agencies. Visits were also made in 3 of those States to 9 home health aide vendor agencies with whom 6 of the 16 home health agencies contracted for aide services. In other words, these vendor agencies are in the business of providing home health aide services to certified home health agencies, and we wanted to look at that situation and exactly how it worked.

We had discussions with 194 people, respondents in these seven States that I mentioned earlier, and in addition, five other States, those five States being: Colorado, Iowa, Michigan, Minnesota, and Ohio. So we had 12 States altogether involved in the study, and additionally we gathered some information from five additional States—Florida, Iowa, Louisiana, Oregon, and Virginia.

The findings of our study raised concerns about the overall quality of care provided by home health aides. While aides perform most of the assigned personal care services—that is, such things as taking care of the hair, the teeth, bathing, homemaking services, meal preparation, that sort of thing, they only provide half of what we call supportive specialized services. These are services analogous to the services that you have on the board up there.

Our first finding highlights the fact that Medicare patients needs for home health aide services are in fact not being met. We reviewed a total of 48 patient records, and that review revealed that where the plans of care called for these specialized services which supported skilled nursing services or physical therapy services, that the aides failed to document and perform half of these tasks.

2 See p. 81.
The nonperformance of these tasks deprives the Medicare patient of the full benefit of the home care program and could result, in our view, in a patient not realizing full rehabilitation potential or in a patient's condition worsening to a point where hospitalization may be required.

A review of the patient records also revealed that home health aides always delivered the personal care services, such as, as I mentioned earlier, baths, care of the mouth, skin, hair, assisting to the bathroom, bedpans, and preparing meals. Consequently, the aide is more or less viewed as a personal caregiver, and this perception contributes to the failure on the part of aides to provide these specialized services.

Second, we found that Federal standards, in the view of many affected by those standards, are not as extensive or as specific as they need to be. The Medicare condition of participation for home health aides lacks standards for recruitment, hiring, and training.

Further, the standards for assignment of aides and supervision do not provide sufficiently objective criteria. As a result, State agencies responsible for surveying the home health agencies for compliance with the conditions of participation find the survey process difficult to perform effectively.

Many States provide standards with specific criteria for the training of home health aides, although these standards vary with regard to training curriculum, length, and content.

In addition, low priority is placed by States on home health surveys. This limits the size of the survey staff as well as the number of surveys performed.

Finally, we noted problems with agency practices in employing aides. Recruitment, hiring, and retention of home health aides are major problems for many agencies, which offer low pay and few fringe benefits. These factors preclude retention of reliable employees, and some agencies experience a very high turnover rate. Other agencies that provide a fair wage and good fringe benefits, however, assure effective selection and retention of aides by offering many incentives.

Poor supervision of aides is the main reason or a primary reason for the failure to provide ordered care. Substantial weaknesses were noted in the supervising nurse's orientation of aides to the needs of patients. These weaknesses were directly related to the absence of clear and comprehensive Medicare standards for home health aides. Improvements in Medicare standards are needed to upgrade the quality of care provided by aides and to assure that the estimated $650 million that Medicare will pay for aide services in 1987 will not be wasted.

We have made a number of recommendations that play off of these findings, to the Health Care Financing Administration, to help overcome some of the problems that we have highlighted in the report. These recommendations are being reviewed now by the Health Care Financing Administration and, based on the back-and-forth that we have with them, may necessarily need to be modified.

A list of the recommendations as we have made them, based on our findings, is included in the draft report already submitted to the committee, and of course we are happy to submit a copy of the final report when it becomes finalized, to the committee.
This concludes my statement, and I am available to try to answer any questions that you may have, Mr. Chairman.

[The prepared statement of Mr. Nicholson follows:]
GOOD MORNING. I AM DON NICHOLSON, ASSISTANT INSPECTOR GENERAL
FOR ANALYSIS AND INSPECTIONS OF THE DEPARTMENT OF HEALTH AND
HUMAN SERVICES.

I AM HERE THIS MORNING AT THE REQUEST OF THE COMMITTEE ON
AGING TO PRESENT TO THE MEMBERS THE FINDINGS OF OUR DRAFT
REPORT, HOME HEALTH AIDE SERVICES FOR MEDICARE PATIENTS. IF
THE COMMITTEE DESIRES, I WILL SUBMIT A COPY OF OUR FINAL
REPORT FOR THE RECORD.

THE OFFICE OF INSPECTOR GENERAL PRODUCES MANY REPORTS DURING
THE YEAR ON THE VARIOUS PROGRAMS OPERATED BY THE DEPARTMENT
OF HEALTH AND HUMAN SERVICES. INCLUDED ARE AUDIT AND
INVESTIGATIVE REPORTS AS WELL AS INSPECTION STUDIES DONE BY
THE OFFICE OF ANALYSIS AND INSPECTIONS. INSPECTION REPORTS
ARE EXAMINATIONS OF ISSUES OF SIGNIFICANT IMPORTANCE TO THE
SECRETARY, THE INSPECTOR GENERAL OR KEY DEPARTMENTAL
COMPONENT HEADS. WE UNDERTAKE THESE STUDIES AFTER CAREFUL
RESEARCH AND REVIEW OF THE ISSUES AND THEIR HISTORY. ONLY
WHEN THE ISSUES INDICATE THAT THIS IS A PROBLEM WORTHY OF
FURTHER ANALYSIS, DO WE UNDERTAKE AN INSPECTION. SUCH IS THE
CASE WITH HOME HEALTH AIDES.

INTRODUCTION

HEALTH AND PERSONAL CARE SERVICES PROVIDED TO ELIGIBLE
PATIENTS AT HOME ARE REIMBURSED UNDER MEDICARE. THESE
SERVICES INCLUDED SKILLED NURSING, PHYSICAL, SPEECH AND
 OCCUPATIONAL THERAPY, MEDICAL SOCIAL SERVICES AND SERVICES
PROVIDED BY HOME HEALTH AIDERS, INCLUDING PERSONAL CARE. THEY
MUST BE ORDERED BY A PHYSICIAN AND PROVIDED THROUGH A
MEDICARE-CERTIFIED HOME HEALTH AGENCY. COVERAGE BY MEDICARE IS ALSO DEPENDENT UPON A HOMEBOUND PATIENT’S NEED FOR THE PART-TIME OR INTERMITTENT SERVICES OF NURSES AND OTHER SKILLED PROFESSIONALS. THE COVERAGE OF HOME HEALTH AIDE SERVICES IS CONTINGENT UPON THE NEED FOR SKILLED PROFESSIONAL SERVICES.

IN 1985, MEDICARE REIMBURSED, AT A COST OF APPROXIMATELY $2 BILLION, NEARLY 6,000 CERTIFIED HOME HEALTH AGENCIES (HMA’S) FOR ALL SERVICES. BY 1990, WE ESTIMATE THAT AS MANY AS 2.2 MILLION PATIENTS WILL BE RECEIVING HOME HEALTH VISITS, AND AS MANY AS 30 PERCENT OF THOSE VISITS WILL BE MADE BY HOME HEALTH AIDES. AIDES WILL CONTINUE TO SPEND TRIPLE THE AMOUNT OF TIME IN A PATIENT’S HOME AS OTHER SKILLED PROFESSIONALS.

IN ORDER FOR A HOME HEALTH AGENCY TO PARTICIPATE IN THE MEDICARE PROGRAM, IT MUST MEET CERTAIN CONDITIONS OF PARTICIPATION STANDARDS. THESE STANDARDS, AS EMBODIED IN REGULATIONS, COVER SUCH AREAS AS ORGANIZATION, ADMINISTRATIVE ACCOUNTABILITY, FINANCIAL PLANNING AND BUDGETING, RECORDKEEPING, THE PROVISION OF HEALTH SERVICES AND QUALITY ASSURANCE PROCEDURES.

THE REGULATIONS ALSO IDENTIFY TASKS WHICH HOME HEALTH AIDES ARE TRAINED TO PERFORM AND DUTIES WHICH THEY MAY BE ASSIGNED BY A REGISTERED NURSE. HOWEVER, TASKS AND DUTIES RELATED TO PERSONAL CARE ARE NOT CLEARLY DEFINED, BUT MAY INCLUDE:

A. PERSONAL CARE SERVICES, SUCH AS:

- HELPING THE PATIENT WITH BATH, CARE OF MOUTH, SKIN AND HAIR;

- HELPING THE PATIENT TO THE BATHROOM OR IN USING BED PANS AND CHANGING THE PATIENT’S BED LINEN; AND

- ASSISTING WITH MEAL PREPARATION AND HOUSEHOLD SERVICES ESSENTIAL TO HEALTH CARE AT HOME TO MAINTAIN A CLEAN, HEALTHFUL AND PLEASANT ENVIRONMENT.
B. SELECTED SKILLED NURSING SERVICES, SUCH AS:

- Assistance with medications that are ordinarily self-administered;
- Simple exercises;
- Specific treatments;
- Clinical observations and nutrition; and
- Completing appropriate records.

C. SELECTED REHABILITATION SERVICES, SUCH AS:

- Assistance with ambulation and exercises as an extension of skilled therapy services; and
- Reporting changes in the patient's condition to the supervising nurse or therapist.

The Social Security Act, specifically Section 1861(m)(4), requires home health aide services provided to Medicare patients to be "part-time or intermittent." Also, home health aides are required to have "successfully completed a training program approved by the Secretary."

The certification of HHAs is carried out by the Health Care Financing Administration (HCFA) through the efforts of state survey agencies. Home care agencies must be licensed in states which require such licensure.

OUR INSPECTION

Our inspection was designed to look at the type and number of services provided to Medicare beneficiaries by home health aides and the training and supervision of the aides who are required to perform the necessary services. Our study included onsite visits in seven states (California, Illinois, Connecticut, New York, Pennsylvania, Tennessee and Texas) to
16 SELECTED MEDICARE CERTIFIED HOME HEALTH AGENCIES (HHA'S). VISITS WERE ALSO MADE IN THREE OF THOSE STATES TO NINE AID VENDOR AGENCIES WITH WHOM SIX OF THE 16 HHA'S CONTRACT FOR AIDE SERVICES. DISCUSSIONS WERE HELD WITH 194 RESPONDENTS IN THESE STATES AND IN FIVE OTHER STATES (COLORADO, IOWA, MICHIGAN, MINNESOTA AND OHIO). INFORMATION ON STATE STANDARDS WAS ALSO PROVIDED BY FLORIDA, IOWA, LOUISIANA, OREGON AND VIRGINIA.

MAJOR FINDINGS

THE FINDINGS OF OUR STUDY RAISED CONCERNS ABOUT THE OVERALL QUALITY OF CARE PROVIDED BY HOME HEALTH AIDES. WHILE AIDES PERFORM MOST OF ASSIGNED PERSONAL CARE SERVICES, THEY PERFORM HALF OF THE SUPPORTIVE SPECIALIZED SERVICES.

OUR FIRST FINDING HIGHLIGHTS THE FACT THAT MEDICARE PATIENT'S NEEDS FOR KEY HOME HEALTH AIDE SERVICES ARE NOT BEING MET.

A REVIEW OF PATIENT RECORDS REVEALED THAT WHERE THE PLANS OF CARE CALLED FOR SPECIALIZED SERVICES IN SUPPORT OF THE DUTIES OF SKILLED NURSES OR PHYSICAL THERAPISTS, THE AIDES FAILED TO DOCUMENT AND PERFORM. HALF OF THESE TASKS. THE NON-PERFORMANCE OF THESE TASKS DEPRIVES THE MEDICARE PATIENT OF THE FULL BENEFIT OF THE HOME CARE PROGRAM, AND COULD RESULT IN A PATIENT NOT REALIZING FULL REHABILITATION POTENTIAL, OR IN A PATIENT'S CONDITION WORSENING TO THE POINT WHERE RE-HOSPITALIZATION IS REQUIRED.

THE REVIEW OF PATIENT RECORDS ALSO REVEALED THAT HOME HEALTH AIDES ALWAYS DELIVERED PRESCRIBED PERSONAL CARE SERVICES, SUCH AS HELPING PATIENTS WITH BATHS, CARE OF MOUTH, SKIN AND HAIR, ASSISTING THEM TO THE BATHROOM OR IN USE OF BED PANS AND PREPARING MEALS FOR THEM. CONSEQUENTLY, THE AIDE IS VIEWED AS A PERSONAL CARE GIVER. THIS PERCEPTION CONTRIBUTES TO THE FAILURE OF AIDES TO PROVIDE SPECIALIZED SERVICES.

SECONDLY, WE FOUND THAT FEDERAL STANDARDS WERE NOT BEING PROVIDED.

THE MEDICARE CONDITION OF PARTICIPATION FOR HOME HEALTH AIDES LACKS STANDARDS FOR RECRUITMENT, HIRING AND TRAINING.
FURTHER, THE STANDARDS FOR ASSIGNMENT OF AIDES AND SUPERVISION DO NOT PROVIDE SUFFICIENTLY OBJECTIVE CRITERIA. AS A RESULT, STATE AGENCIES RESPONSIBLE FOR SURVEYING HOME HEALTH AGENCIES FOR COMPLIANCE WITH THE CONDITIONS OF PARTICIPATION FIND THE SURVEY PROCESS DIFFICULT TO PERFORM EFFECTIVELY. MANY STATES PROVIDE STANDARDS WITH SPECIFIC CRITERIA FOR THE TRAINING OF HOME HEALTH AIDES. ALTHOUGH THESE STANDARDS VARY WITH REGARD TO TRAINING CURRICULUM LENGTH AND CONTENT. IN ADDITION, LOW PRIORITY IS PLACED BY STATES ON HOME HEALTH SURVEYS. THIS LIMITS THE SIZE OF SURVEY STAFFS AS WELL AS THE NUMBER OF SURVEYS PERFORMED.

FINALLY, WE NOTED PROBLEMS WITH AGENCY PRACTICES IN EMPLOYING AIDES.

RECRUITMENT, HIRING AND RETENTION OF HOME HEALTH AIDES ARE MAJOR PROBLEMS FOR MANY AGENCIES WHICH OFFER LOW PAY AND RELIABLE EMPLOYEES AND EXPERIENCE A VERY HIGH TURNOVER RATE. OTHER AGENCIES, HOWEVER, ASSURE EFFECTIVE SELECTION AND RETENTION OF AIDES BY OFFERING MANY INCENTIVES, INCLUDING GOOD PAY, BENEFITS AND PARAPROFESSIONAL STATUS.

POOR SUPERVISION OF AIDES IS THE MAIN REASON FOR THE FAILURE TO PROVIDE ORDERED CARE. SUBSTANTIAL WEAKNESSES WERE NOTED IN THE SUPERVISING NURSES' ORIENTATION OF AIDES TO THE NEEDS OF PATIENTS. THESE WEAKNESSES WERE DIRECTLY RELATED TO THE ABSENCE OF CLEAR AND COMPREHENSIVE MEDICARE STANDARDS FOR HOME HEALTH AIDES. IMPROVEMENTS IN MEDICARE STANDARDS ARE NEEDED TO UPGRADE THE QUALITY OF CARE PROVIDED BY AIDES AND TO ASSURE THAT THE ESTIMATED $650 MILLION MEDICARE WILL PAY FOR AID SERVICES IN 1987 WILL NOT BE WASTED.

CONCLUSION:

WE HAVE MADE A NUMBER OF RECOMMENDATIONS TO HCFA TO HELP OVERCOME SOME OF THE PROBLEMS HIGHLIGHTED IN OUR REPORT. THESE RECOMMENDATIONS ARE BEING REVIEWED BY HCFA AND BASED ON ANY COMMENTS WE RECEIVE, MAY BE MODIFIED. A LIST OF THESE RECOMMENDATIONS ARE INCLUDED IN OUR DRAFT REPORT FOR YOUR REVIEW.

THIS CONCLUDES MY STATEMENT. I AM AVAILABLE TO ANSWER ANY QUESTIONS.
The Honorable John Melcher  
Chairman, Committee on Aging  
United States Senate  
Washington, D.C. 20510

Dear Mr. Chairman:

This is in response to your letter of April 2, 1987 concerning an Office of Inspector General report on Home Health Agencies (HHAs).

Our office has recently conducted a study in order to help the Department of Health and Human Services and other interested parties obtain a picture of home health aide services provided to Medicare patients. Our study findings are based upon discussions with HHA and vendor administrative personnel, State surveyors, physicians, nurses, Medicare patients and others in the home care industry of 16 selected Medicare certified HHAs in seven States. We are pleased to share with you our draft report entitled "Home Health Aide Services for Medicare Patients."

The findings of our study raised concern about the overall quality of care provided by home health aides. While aides performed most of the assigned personal care services, they failed to perform supportive specialized medical services. We believe the non-performance of these tasks deprives the Medicare patient of the full benefit of the home care program, and could result in a patient not realizing full rehabilitation potential, or in a patient's condition worsening to the point where re-hospitalization is required. Since the Medicare program is already paying for visits of sufficient length to accommodate more specialized services of aides, the Medicare program is paying for aide services not rendered. We are recommending that the Department take various steps to tighten the provision of home health aide services. This report is currently circulating within the Department for review and comment.

The study was directed by Tom Tully our Regional Inspector General in the New York Office of Analysis and Inspections. Inquiries concerning the study report and findings may be directed to him at (212) 264-5295.

Sincerely yours,

Richard P. Kusserow  
Inspector General

Enclosure
Office of Inspector General

The mission of the Office of Inspector General (OIG) is to promote the efficiency, effectiveness and integrity of programs in the United States Department of Health and Human Services (HHS). It does this by developing methods to detect and prevent fraud, waste and abuse. Created by statute in 1976, the Inspector General keeps both the Secretary and the Congress fully and currently informed about programs or management problems and recommends corrective action. The OIG performs its mission by conducting audits, investigations and inspections with approximately 1,200 staff strategically located around the country.

Office of Analysis and Inspections

This report is produced by the Office of Analysis and Inspections (OAI), one of the three major offices within the OIG. The other two are the Office of Audit and the Office of Investigations. OAI conducts inspections which are typically short-term studies designed to determine program effectiveness, efficiency and vulnerability to fraud or abuse.

This Report

The report is entitled, "Home Health Aide Services For Medicare Patients." It was prepared following a review conducted to help the Health Care Financing Administration and other interested parties gain a current overview of the role of the home health aide in meeting Medicare patients' needs for home health care, and the standards and process by which home health aide services are evaluated.

The study was prepared by the Regional Inspector General, Office of Analysis and Inspections, Region II. Participating in the project were the following people:

New York Region:  
Joseph J. Corso, Jr. (Project Leader)  
Lucille Cop, R.N.  
Alan Levine  
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HOME HEALTH AIDE SERVICES
FOR MEDICARE PATIENTS

RICHARD P. KUSSEROW
INSPECTOR GENERAL

Control # OAI-02-86-00010

APRIL 1987

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EXECUTIVE SUMMARY

The findings of our study raised concerns about the overall quality of care provided by home health aides. While aides perform most of assigned personal care services they perform half of the supportive specialized services.

MAJOR FINDINGS

I. MEDICARE PATIENTS' NEEDS FOR KEY HOME HEALTH AIDE SERVICES ARE NOT BEING MET

* A review of patient records revealed that where the plans of care called for specialized services in support of the duties of skilled nurses or physical therapists, the aides failed to document, and perform, half of these tasks. The non-performance of these tasks deprives the Medicare patient of the full benefit of the home care program, and could result in a patient not realizing full rehabilitation potential, or in a patient's condition worsening to the point where re-hospitalization is required.

* Since the Medicare program is already paying for visits of sufficient length to accommodate more specialized services of aides, the Medicare program is paying for aide services not rendered.

* We found that poor supervision of aides is the main reason for the failure to provide ordered care. Substantial weaknesses were noted in the orientation of aides to the needs of patients by supervisory nurses and in the supervision given to the aides in the patients' homes.

* The review of patient records also revealed that home health aides always delivered prescribed personal care services, such as helping patients with baths, care of mouth, skin and hair, assisting them to the bathroom or in use of bed pans and preparing meals for them.

* The aide is viewed as a personal care giver. This perception contributes to the failure of aides to provide specialized services.

* Serious problems were noted with agencies' use of home health aides under contract. These include: Medicare patient vulnerability to substandard practices and services which are unnecessarily time consuming, frequent and costly.

II. STANDARDS NOT PROVIDED

* The Medicare Condition of Participation for home health aides lacks standards for recruitment, hiring and training. The standards for assignment of aides and supervision do not provide sufficiently objective criteria. As a result, State agencies responsible for surveying home health agencies for compliance with the Condition of Participation find the survey process difficult to perform effectively. Many States provide standards with specific criteria for the training of home health aides, although these standards vary with regard to training curriculum length and content.

* Improvements in Medicare standards are needed to upgrade the quality of care provided by aides, and to assure that the estimated $650 million Medicare will pay for aides services in 1987 will not be wasted.

* Low priority is placed by States on home health surveys. This limits the size of survey staffs as well as the number of surveys performed.
III. PROBLEMS NOTED WITH AGENCY PRACTICES IN EMPLOYING AIDES

- Recruitment, hiring and retention of home health aides are major problems for many agencies which offer low pay and limited benefits. These agencies do not attract the most reliable employees and experience a very high turnover rate.

- Other agencies, however, assure effective selection and retention of aides by offering many incentives, including good pay, benefits and paraprofessional status.

MAJOR RECOMMENDATIONS

I. The Health Care Financing Administration (HCFA) should direct State survey agencies, through training programs and written instructions, to review selected plans of care and the corresponding patient medical records to assure that all prescribed tasks are performed and documented by home health aides. Training and instruction of State surveyors is essential to assure that the Condition of Participation for aides is satisfied.

II. HCFA should provide State survey agencies with administrative guidelines for assisting home health agencies in the selection, training, assignment and supervision of aides. This will prepare surveyors to help home health agencies correct deficiencies found during the survey process.

III. HCFA should encourage:

- States without specific State regulations on the training of home health aides to develop a curriculum for training home health aides, or adopt an existing curriculum. Completion of an established training program should be a prerequisite of a home health aide position.

- Organizations such as the National Houching Council, National Association For Home Care and the Joint Commission on the Accreditation of Hospitals to work with their members to improve home health aide services through more effective training and supervision.

IV. HCFA should revise those sections in the Health Insurance Manual for home health agencies and fiscal intermediaries (PI's) which deal with services provided by home health aides. The revisions should distinguish between personal care services and those services representing extensions of skilled care, indicating that all tasks in the plans of care are expected to be performed by aides during each visit.

V. HCFA should revise the Home Health Agency Coverage Compliance Review instructions to PI's. Revised instructions should expand the points to be addressed by the PI's during onsite reviews to include comparison of aide tasks specified in plans of care with aide tasks performed, to assure that plans of care tasks for aides are fully implemented.

VI. HCFA should review home health aide services provided under a contract to determine whether a limitation on such services would be appropriate, in view of the findings that aides under contract:

- did not perform the majority of extensions of skilled care tasks assigned to them;

- subjected Medicare patients to substandard practices; and

- made visits which were unnecessarily time consuming, frequent and costly.
INTRODUCTION

Covered health and personal care services provided to eligible patients at home are reimbursed under Medicare. These services include skilled nursing, physical, speech and occupational therapy, medical social services and services provided by home health aides, including personal care. They must be ordered by a physician and provided through a Medicare-certified home health agency. Coverage by Medicare is also dependent upon a homebound patient's need for the part-time or intermittent services of nurses and other skilled professionals. The coverage of home health aide services is contingent upon the need for skilled professional services.

Medicare reimbursement to nearly 6,000 certified home health agencies (HHA's) for all services in 1985 is estimated to be about $2 billion. By 1990, as many as 2.2 million patients will be receiving home health visits, and as many as 30 percent of those visits will be made by home health aides at a cost of about $750,000,000. Aides will continue to spend triple the amount of time in a patient's home as skilled professionals.

In order for an HHA to participate in the Medicare Program, it must meet the Conditions of Participation. These standards, set forth in 42 CFR 405.1227, cover such areas as organization, administrative accountability, financial planning and budgeting, recordkeeping, the provision of health services and quality assurance procedures.

42 CFR 405.1227 outlines the single Medicare Condition of Participation and two standards that home care agencies must meet concerning home health aide services. Outlined in summary form below, they include the following requirements:

- **Hiring** – aides are able to read, write, and carry out directions, and are mature and capable enough to deal with sick patients.
- **Training** – aides are carefully trained in assisting patients to achieve maximum self-reliance.
- **Assignment of Duties** – aides are assigned specific duties by a registered nurse.
- **Supervision** – aides are closely supervised by a registered nurse or other professional staff every two weeks.

The regulation also identifies tasks which home health aides are trained to perform and duties which they may be assigned by a registered nurse. The regulation does not always define tasks and duties, such as "personal care", but they may be grouped into three categories and include the following:

1. **Personal Care Services.** Helping patient with bath, care of mouth, skin and hair, helping patient to bathroom or in using bed pan, changing patient's bed linens, assisting with meal preparation and household services essential to health care at home to maintain a clean, healthful and pleasant environment. Completing appropriate records.
2. **Extension of Skilled Nursing Services.** Assistance with medications that are ordinarily self-administered, simple exercises, specific treatments, clinical observations and nutrition, reporting changes in the patient's condition to the supervising nurse. Completing appropriate records.
3. **Extension of Rehabilitation Services.** Assistance with ambulation and exercises as an extension of skilled therapy services. Reporting changes in the patient's condition to the supervising nurse or therapist. Completing appropriate records.

Section 1861(m)(4) of the Social Security Act requires home health aide services provided to Medicare patients to be "part-time or intermittent" and also requires home health aides to have "successfully completed a training program approved by the Secretary." The certification of HHA's is carried out by the Health Care Financing Administration (HCFA) through the efforts of State survey agencies. Home care agencies must be licensed in States which require such licensure.
FINDINGS

MEDICARE PATIENTS' NEEDS FOR SOME KEY HOME HEALTH AIDE SERVICES ARE NOT BEING MET

1. Plans of Care Not Being Followed

All 62 patient records reviewed contained plans of care which called for aides to perform tasks representing personal care services; 85 percent of the plans also called for aides to perform tasks which represented an extension of nursing or rehabilitation services. Examples of the tasks found in plans of care in support of nursing services included the following: assisting with dialysis, diabetic monitoring (urine testing), catheter care, foot soaks; special skin care; observation and notation of changes in respiratory condition; encouraging intake of fluids; recording intake and output of fluids; taking of temperature, pulse and respiration with readings noted. For rehabilitation, it was noted that aides were often asked to help with exercises, transfers to and from bed and ambulation training as taught by the physical therapist and recording progress in activities of daily living.

A comparison of the 62 aide plans of care with corresponding aide activity sheets revealed that prescribed personal care tasks were always documented as having been performed. However, in 48, or 91 percent, of the 53 cases where extensions of skilled services were prescribed, one or more tasks were not documented by the aides as having been performed. In half of these cases, one or more of those tasks were never documented; in the other half, one or more of those tasks were only occasionally documented. Overall, nearly half of the prescribed extension tasks expected to have been performed during more than 1,600 aide visits were not documented.

Responses from both patients and aides support the conclusion that all personal care tasks were actually performed. Responses also support the conclusion that a lack of documentation indicates that the extension tasks were not performed by the aides.

Since the services provided by home health aides as an extension of nursing or rehabilitation services are intended to be a continuum of skilled care, failure to provide the services deprives the patient of the full benefit of the home care program. A patient who has a therapy treatment twice a week without any aide-assisted "practice" between skilled visits may not achieve her/his full rehabilitation potential as quickly, if at all. When key observations are not made by an aide or are not noted for the nurse, the patient's condition may worsen, and skilled treatment essential to the patient's recovery might not be started.

Special treatments assigned to aides, such as foot soaks or special skin care, if not performed, could lead to serious skin deterioration. In cases of this kind, patients may require re-hospitalization.

To gain an insight as to why so many aide tasks were not documented and apparently not performed, the inspection team made follow-up contacts with supervising nurses and administrative personnel of a number of HHA's which had been previously visited. The consensus of these respondents was that the primary and continuing cause of the problem was the lack of orientation of aides by supervising nurses to patient cases and tasks as well as the lack of ongoing onsite supervision of aides by professionals.

One respondent said:

The start-up visit is essential in every single case to introduce the aide, give the case plan and demonstration of tasks. The supervision every two weeks must be onsite with the aide.

Another respondent indicated that extension tasks were not performed by aides because they are usually alone with patients and lack confidence without the proper support of skilled professionals. She said:
The aide may be fearful of doing a procedure if they are not shown it specifically. They are aware they might hurt a patient and get into trouble if they do it wrong. The therapist or nurse must meet with the aide in the home and show them what should be done.

One respondent said that the assignment of multiple aides to the same patient precluded supervision. Nurses cannot orient and supervise multiple aides effectively, nor assure uniformly effective performance of tasks. She also said that it was a good practice to have aides present at patient conferences with skilled professionals, but that practice was discontinued at her agency.

Other causes cited by respondents included deficiencies in aide training, especially in the area of documenting tasks performed. It was noted that since many aides lack language skills to articulate tasks performed, many agencies frequently have aides use a checklist to identify those tasks.

2. Majority Of Undocumented Tasks Were Assigned To Vendor Aides

Medicare requires HHA's to meet all standards for home health aide services, whether or not the services are provided directly or under contract. HHA's must assure that vendors they contract with also meet the Medicare standards for aide services.

Among the 44 home health aides providing services to the 62 patients, 15 were employees of vendors contracting with six of the 16 HHA's, and three were under direct contract to a seventh HHA. Over one-half of the aides were employees of 12 HHA's (three also contracted for some aide services and fell into both groups). The chart below summarizes the documentation of extension tasks by both groups of aides for the 48 patients visited.

<table>
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<tr>
<th>Aides</th>
<th>Patients</th>
<th>Visits</th>
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<th>Undocumented Tasks</th>
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<td>3,782</td>
<td>1,841 (49%)</td>
</tr>
</tbody>
</table>

3. Vendor Aide Visits Tend To Be Long, Frequent And Costly

The average length of visit for the first group of 18 aides was 2.6 hours, while the second group of 26 aides spent an average of 1.8 hours on each visit. Three HHA's in one Eastern State, where contracting for aide services is prevalent, allow vendor aides to spend as much as four hours on each home visit. Staff aides of the other HHA's spend under two hours per visit. Vendor aides also average more visits per week than staff aides. Because of high turnover among aide staff, vendors try to place aides on cases for longer periods of time with minimal travel. In addition, labor union agreements affecting many vendor aides make it costlier per hour to place those aides in a patient's home for less than three hours. For example, one union agreement with a vendor stipulates that aides will be paid $1 more per hour on visits of under three hours.

4. Lack Of Control Over Vendor Aides Makes HHA Patients Vulnerable To Substandard Practices

In 1985, six of the 16 sample HHA's in three Eastern States contracted with 18 vendors for all or part of the nearly 150,000 home health aide visits provided to Medicare patients. Of those total visits, 72 percent were made by vendor aides the six HHA's did not recruit, hire, train or assign to patient cases. These HHA's assured vendor aides complied with standards in various and often effective
ways. In addition, it was found that vendors' deficiencies discovered by some HHA's were not reported to Medicare authorities and were not always corrected. One HHA conducted 1984 and 1985 annual audits of one of its vendors. Out of 165 aide personnel files audited, 211 deficiencies were found. Areas of deficiency included physical exams, health tests and immunizations, references, and in-service training.

Out of a small sample of 15 Medicare patients and vendor aides visited by the inspection team in three Eastern States, there was one case where the aide did not arrive at the patient's home when expected: the patient was a wheelchair-bound amputee on dialysis who lived alone. Another problem case involved a vendor aide who did not show up at the patient's home as scheduled for four days. Neither the vendor nor the HHA was aware of it, until the patient complained. Some state surveyors and supervisory nurses said this occurs frequently.

5. Supervision of Home Health Aides Is Found to be Inconsistent and Ineffective, Especially When Multiple Aides Visit the Same Patient

The previously noted comments on poor supervision were supported by the inspection team's observations during the study. Weaknesses were noted in the areas of aide orientation and on-the-job training for individual patients by supervisory nurses. How supervision is to be carried out is not specified by Medicare regulations, although registered nurses must make supervisory visits every two weeks, with or without the aide's presence. Many supervising nurse and agency respondents believe that aide orientation and on-the-job training for specific patients, when conducted by supervising nurses, is the only effective way to assure that all prescribed tasks are properly performed.

There was evidence that aides were given an orientation by the supervising nurse on the first aide visit in only 22 percent of cases reviewed. This orientation introduces the aide to the patient and family, and allows for discussing the home environment and reviewing the plan of care. Demonstrations of tasks are given by the nurse followed by return demonstrations by the aide. Orientation is considered more important when prescribed aide tasks include extensions of skilled services.

When HHA's and vendors substitute aides on patient cases, the supervising nurse visits do not effectively serve the purpose intended. Orientation to the patient and on-the-job training should be repeated for each aide, but often are not. One nurse supervising vendor aides said:

Ideally we will be there at the aides' first visit to orient her to the tasks. If not possible, I could make a telephone call. I always make an effort to be onsite the first time to teach the aide, but the aide changes and I can't always go in every time. It is a frustration!

A senior agency official of one of the HHA's advised that "rotation of aides" was based on assigning the more experienced aides to new problem cases. However, a vendor official with more direct involvement in assignment of aide staff to the HHA's patients advised that part-time vendor aides paid an hourly rate are usually taken off cases to give work to vendor full-time aides who are salaried. A common complaint from ex-patients of this agency is "too many different aides."

Documentation in two-thirds of the patient cases indicates supervising nurse visits were not made when the aide was present. Medicare regulations do not specify that the aide must be present. One nurse emphasized the importance of coordinating supervisory visits with aides when she said:

At least once a month there should be onsite supervision while the aide is in the home. Personally, I wouldn't want to be responsible for an aide if I didn't see her performance.
Although some nurses expressed difficulty coordinating their visits with the aide in the home, many felt it was essential to good care.

6. Aides Are Perceived As Primarily Personal Care Workers

We learned from our discussions with patients, aides and supervising nurses, that home health aides are generally perceived as "caring companions" whose most important functions are to keep patients clean, lend emotional support to patients and family and provide some housekeeping services. Expectations for aides seldom encompass duties to assist patients in achieving maximum self-reliance.

Eighty percent of all patient, aide and nurse respondents identified personal care, especially bathing, as the most important service aides provide. Emotional support of patients and families ranked as the second most important service provided by aides. Where family members lived with patients, aide visits were seen as providing a needed respite from looking after the patient. While the third-ranking service according to patients and aides was housekeeping, the third-ranking service in the view of nurses was the extension of either nursing or rehabilitation services.

One agency utilized aides primarily for providing limited personal care services, regardless of the need of its patients for other services aides are normally expected to provide. All four patients from this agency had plans of care calling for "personal care and bath" only; two of the four patients had received physical therapy, but the aides' plans of care in those cases did not call for any tasks in support of the rehabilitation services. The R.P.T. member of the inspection team felt that an extension of rehabilitation services by the aides in these cases was appropriate and would have been beneficial to the patients. Aides indicated that this agency also does not allow them to do housekeeping, meal preparation or shopping. Such services may be covered by Medicare and appropriate for specific patients.

Where aides did not carry out the tasks considered extensions of skilled services, the length of visits did not appear to be a major factor. In those cases, aide visits were as brief as 45 minutes and as long as four hours, averaging about two hours per visit, usually a sufficient time to complete assigned tasks. Medicare fiscal intermediaries routinely reimburse agencies for aide visits assuming all tasks were performed as prescribed in plans of care.

STANDARDS NOT PROVIDED

1. Medicare Regulations For Home Health Aides Are Not Adequate

Surveyors in 11 of the 12 States contacted view Medicare regulations as barely adequate, or even inadequate, in helping them do their job. A typical complaint was that Medicare regulations "have too many gaps and are open to too much interpretation." Others cited the lack of training standards as a major weakness. "There's a real void in the Medicare regulations there," said a surveyor in a Western State. Another deficiency noted was the lack of a standard for the selection of aides.

A review of the Medicare Condition of Participation for home health aides and its two specific standards indicates very few criteria. There are no specific standards for the selection and training of home health aides. For example, the Condition states that aides should be "carefully trained", but it does not specify curriculum content or length, or required classroom and clinical hours, or the need for continuing (in-service) education or on-the-job training.

In one of the two areas where the Condition does establish a standard, which requires assignment of aides to cases to be made only by a registered nurse, there are no criteria which provide a basis for the assignment such as patient needs and the abilities of specific aides. The other
Medicare standard deals with aide supervision. While it requires that a registered nurse or other appropriate professional supervise the aide, it does not specify that the aide must be present during supervision.

2. Application Of Medicare Regulations Is Subjective; Guidelines Offer Limited Help

The decision by State surveyors as to whether agencies meet the overall Condition of Participation is largely left to the surveyor's subjective judgment. Consequently, while elements of the Condition (selection or training of aides) or standards (assignment of duties and supervision of aides) may be out of compliance, surveyors may still determine that the Condition is met. The only enforcement power to assure correction of specific deficiencies by non-compliant agencies is an involved decertification process which is rarely used.

Several surveyors indicated that HCFA's interpretive guidelines for survey agencies offered them little help in applying Medicare regulations during the survey process. Some criteria are provided for the assignment of aides to patients and there is a reference to "continuing staff education" being provided to aides. But HCFA guidelines say nothing about how many failures to comply with elements or standards are permitted before the Condition of Participation is judged "Not met." One surveyor indicated that failure to meet either or both standards would always be cited as deficiencies but would rarely be enough to find the Condition not met.

3. Most States Contacted Have Their Own Regulations; They Contain More Specific Criteria For Training Aides Than Medicare Regulations

Of the 16 States queried, 11 said they had their own regulations. Most said that their regulations give surveyors some specific and objective criteria, primarily in the areas of training, to determine an agency's compliance with Medicare regulations. (See Appendix II for listing).

The following elements are significant:

Course Curricula

Training course length is specified in nearly all the States which have their own regulations, with the length ranging from 42 to 230 total hours. Five of the States with regulations require supervised clinical training of from 15 to 30 hours as a prerequisite to successful completion. Prior approval of home health aide training curricula is required by seven States. One State requires training through a uniform curriculum offered statewide by vocational-technical schools and regional community colleges. Another State requires training programs to be equivalent in content and depth to the National Homecaring Council's "Model Curriculum."

Continuing Education

Of the 11 States with their own regulations, the general need for continuing education is cited in five States, while three other States specify that aides receive at least 12 hours of in-service training a year.

Certification Of Successful Completion

A certificate attesting to successful completion of aide training is required in six of the 11 States with regulations, with three States' certificates reflecting State seals and approval of the training. In one State, certificates are issued by the licensing agency directly to the aide with a certificate number kept on permanent registry. The application for the certificate must come from the trainer and attest to the aide's successful completion of a course approved by the State.

Supervision

With regard to supervision, most of the State regulations are the same as Medicare's. Only one State requires that a registered nurse provide direct supervision, i.e., while the aide is present, to the home health aide in the patient's home at least every two weeks.
Since Federal regulations offer few specific criteria, surveyors in the five States which do not have any State regulations experience difficulty when agencies contest findings of non-compliance. These States have developed internal procedures to compensate, e.g., recommending a particular training curriculum as one which meets the Medicare regulations. However, such recommendations do not carry the force of regulations and agencies are not compelled to comply with them. These surveyors indicated they must also spend more time and resources to assure compliance without the benefit of objective criteria. It is much harder to assure that an aide is "carefully trained" where States have no specific criteria mandating a curriculum, or where State regulations do not require prior approval of curricula. One surveyor in the East stated "It would make our job easier if we could simply verify that an agency uses aides that have been certified as passing a training program that is approved."

4. Respondents Want More Specific Medicare Standards

Virtually all the respondents queried, including all surveyors, agreed that having a nationally mandated training standard for home health aides would be useful. Several recommended wider use of the National Humecaring Council's "Model Curriculum" developed in 1978 and used extensively around the country as the basis for many home health aide training programs. One survey nursing consultant said "it would make my job easier. It would improve the quality of work produced, and assure more uniform practices from state to state."

The Chief of another State's Home Health Survey Section recommended "Revisions to include specific criteria for training, i.e., number of hours, curriculum content, composition of faculty and credential requirements."

She also suggested modifying the current Medicare standards for assignment and supervision of aides by the:

... addition of the requirement for orientation of all Home Health Aides to the patient, family and the written instructions of duties. Verification of Home Health Aides' competency to carry out instructions should be clearly documented in the patient's clinical record...

This individual further recommended that "... orientation be added to the responsibilities of the registered nurse (RN) in the Conditions of Participation."

A State surveyor from a State without regulations indicated that former Medicare regulations are still used in that State as a guideline for compliance. These former regulations established four Conditions of Participation, including one each for home health aide services, selection of home health aides, assignment of duties and supervision. All the Conditions contained some specific criteria to be met for compliance.

5. Effective Application Of Medicare And State Regulations Are Limited By Other Problems:

A. Low priority for home health surveys limits survey staff and number of surveys performed.

We found that certified home health agencies are not usually resurveyed annually. Among the 16 home health agencies visited by the inspection team in 1986, one was last resurveyed in early 1986, five in 1985, seven in 1984, one in 1983 and two in 1981. In fact, in most sample States, resurveys are backlogged one to four years. The reasons for the lack of resurveys are:

* Federal/state budget restrictions limit survey resources allocated for home health agencies. Most agencies are surveyed by one or two registered nurses, without other disciplines represented. One State survey agency had only three nurses available in 1985 to cover a growing number of certified agencies, now nearly 300. One State agency official indicated:
The principal problem is adaptation of the Federal budgetary process to State Agency practices. In recent years, budget cuts and time lag in approval of Federal funding for the program has all but eliminated any national planning for maintaining necessary staff and resources to carry out certification activities.

* Home health agency recertifications are given the lowest survey priority by State agencies. The survey staff does give priority to agencies seeking Medicare certification since they get no Medicare reimbursement prior to certification. The dramatic increase in agencies seeking certification over the last five years has heavily taxed State survey resources.

B. Surveys performed are limited by logistical factors.

Certified agencies' branch offices are not usually visited on resurveys, although a sample of some branch office patients may be reviewed as part of a survey. This circumstance is due primarily to two factors:

* The large size of some agencies. Some have as many as 20 branch offices. These branch offices sometimes fall within the survey jurisdiction of more than one of the State's regional survey offices.

* Branch offices are sometimes located hundreds of miles from the parent office, making it impractical and costly for a surveyor to visit them. These branch offices might be sub-units and, as such, subject to independent certification, if criteria for designating an office as a sub-unit were stringently applied.

C. Training for State surveyors has not emphasized home health care.

HCFA training for new and experienced State surveyors has traditionally been built around institutional activity, i.e., hospitals, skilled nursing facilities. Since the fall of 1985, HCFA training has been geared more specifically to home health care. Several survey agencies complained about training and suggested remedial action. One survey agency representative said:

Basic Training sessions for surveyors do not address the Home Health agency survey process. Training sessions for newly hired surveyors, to accommodate changes in State Agency personnel, are not readily available. Advanced training for Home Health agency surveyors is limited or non-existent.

Another surveyor said:

I recommend specific training in home health by HCFA centrally and through regional offices. There has not been enough emphasis on home care in past training. There are currently 200 certified home health agencies in this state and the number is growing. We need more staff and training.

D. Mandated home visits during surveys are not being made.

Home visits during State surveys, required by a recent HCFA directive (November 1985), are not routinely made to Medicare patients in 11 of the 12 States contacted. Some limited experimentation has been tried in several States, but generally implementation is lagging because:

* HCFA has not provided any additional funding for this activity.

* HCFA criteria for implementation are extensive and scheduling visits could add more than a day to the survey process. For example, patient consent for the visit is required, and surveyor sample patients served by branch offices may be located far from the parent office of the agency.

* Many States are skeptical about the efficacy of home visits.
1. Recruitment of Aides Is Costly to Many Agencies;
   Competition for Desirable Workers Is Keen and Employee Turnover Is High

   Forty percent of the home health agencies and aide vendor agencies contacted during the inspection have had major problems recruiting, hiring and retaining aides. The 10 agencies serve primarily urban and suburban areas in three Eastern States and one Southern State. Six of the 10 agencies train the aides they recruit and hire, while four agencies recruit aides already trained or utilize aides provided by vendors under contract.

   All 10 agencies recruit aides through the use of daily and/or weekly newspaper advertising, flyers distributed in local communities, church and merchant bulletin boards and word-of-mouth. Several agencies offer cash bonuses to aide staff for referring candidates. The cost of advertising is high and the number of respondents screened is much higher than those actually interviewed, trained or hired. One agency administrator's statement is typical: "We have suspended recruiting because it was too expensive. Too many people didn't show up for employment interviews. One in twenty came. It was too costly to do screening." Nonetheless, this agency has since returned to recruiting aides for its staff because of great dissatisfaction with the performance of the aides provided by vendors.

   One vendor, which recruits and trains aides in a suburban area, screened nearly 1,000 applicants over the last three years. After an extensive and costly interviewing process, only 411 people were selected for training; of that number, 324 aides were graduated and hired. The major concern expressed by respondents about aides trained under these circumstances was the pressure agencies are often under to assign aides to patients when the aide's ability and reliability are questionable.

   An agency administrator summarized the predominant view of respondents about the hiring and training of aides: "If the future will continue to see paraprofessionals doing more and more for patients, there must be higher standards for training and pay."

   One phenomenon affecting many of the agencies is the movement of a segment of the workforce, made up of mature women, to local employers such as fast food chains. Many of these women are filling jobs previously held by teenagers. Many of the people responding to agency recruitment efforts tend to be looking for transient employment. One vendor indicated that half the aides they train and hire are single parents, some on public assistance, whose reliability is affected by day care and school schedules. Aide turnover rates of from 20 percent to 55 percent annually have perpetuated the recruitment problems of the 10 agencies, making recruitment a constant and costly process.

2. Agencies With Staffing Problems Offer Few Incentives to Assure Effective Selection and Retention of Aides

   Eleven agencies reported problems retaining aides, including the 10 agencies with recruiting problems. One major characteristic of those agencies is that they offer prospective aides the lowest wages and benefits among all the 25 agencies contacted. Agency administrators agreed this was the major reason for hiring and turnover problems. A typical response was "It's hard to keep good aides because of poor pay and lack of benefits." In suburban and rural areas, the aides must provide their own transportation, usually a car, because public transportation is poor or nonexistent. In these cases, a valid license and fully-insured car is also required. One vendor does not reimburse its aides for transportation costs, while others provide reimbursement for mileage between patients' homes only.

   Other disincentives, include:
generally no pay during classroom training which may last up to four weeks.

up to six months work for the agency or vendor before a certificate attesting to the aide's successful completion of the required training is awarded.

no upward mobility opportunities and extremely limited hourly wage increases.

work assignments in some urban areas which are considered dangerous with no additional compensation made for these assignments.

little or no allowance for uniforms.

agency treatment of aides as "second-class" employees rather than paraprofessional members of a home care team.

3. Other Agencies Assure Effective Selection And Retention Of Aides Through Best Practices

The practices of most of the remaining 14 agencies in the sample group have resulted in effective hiring and retention of aides. Incentives offered to prospective employees have assured stable individuals and low or no turnover. Consequently, recruitment has rarely been a problem. Several agencies have waiting lists of prospective employees. Most of the agencies can afford to be selective in filling occasional vacancies.

The practices of these agencies include:

* hiring aides, already trained, who have up to two years of patient care experience.

* offering wages or salaries which provide annual earnings of from $12,000 to $18,000.

* providing extensive health insurance and sick and vacation leave benefits.

* reimbursing travel expenses at rates of $0.18 to $0.28 per mile, or the full cost of public transportation used.

* providing advancement opportunity through significant incremental wage increases for both length of service and effective performance.

* providing opportunities for positions of greater responsibility within the agency, and offering other incentives, such as tuition assistance programs to encourage continuing education in related health careers.

* acknowledging aides as important members of the interdisciplinary home health care team.

4. Agency Practices Limit Efficient Use Of Aide Staff

Agency and vendor administrators agreed that many factors influence the assignment of aides to patients. Although a patient's condition was frequently cited as a main consideration, in practice most assignments appear to have been made based on the availability of the aide, the patient's location and the aide's access to transportation. This was particularly true where vendors provided aides under contract.

Most of the 25 agencies and vendors indicate they try to assign the same aide to a patient for the duration of the plan of care. However, a review of medical records showed 42 percent of the patients had three or more aides assigned to them over a period from one to six months. Vendors frequently substitute aides on cases because of turnover and unreliability of their aide staff.

5. Agency Policies and Practices Influence Length of Aide Visits
Aides in six agencies indicated that the amount of time spent with each patient was influenced by the agencies' policies. A proprietary agency in one Western State requires all home health aide visits to Medicare patients to be two hours, regardless of whether the needs of individual patients require more or less time. One aide from this agency said "Two hours is not enough for certain patients."

A proprietary agency in another Western State contracts directly with individual aides and pays them on a per-visit basis. The aides stated that they spend about 30 to 45 minutes with each patient and see six to eight patients per day. Although they provided personal care services to their patients, including bathing, the taking of temperature, pulse and respiration readings and transferring the patient from bed, one aide said that an hour was needed just to properly bathe patients.

6. Medicare Fiscal Intermediary Policies Affect Agency Practices

Although HCFA policy directives are used by all fiscal intermediaries (FI), respondents in seven States indicated that FI application of policies varied both within States and from State to State. These policies, which have become more restrictive in recent years, have influenced the length and frequency of aide visits provided by most of the 16 agencies. Respondents indicated that services which will be reimbursed will always be provided. Aide services that are frequently denied, based on experience with FI decisions, will be limited or not provided at all.

RECOMMENDATIONS

I. The Health Care Financing Administration (HCFA) should direct State survey agencies, through training programs and written instructions, to review selected plans of care and corresponding patient medical records to assure that all prescribed tasks are performed and documented by home health aides. Training and instruction of State surveyors is essential to assure that the Condition of Participation for aides is satisfied.

II. HCFA should provide State survey agencies with administrative guidelines for assisting home health agencies in the selection, training, assignment and supervision of aides. This will prepare surveyors to help home health agencies correct deficiencies found during the survey process.

III. HCFA should assure that required home visits are made by State surveyors. The criteria for conducting the home visit program should be reevaluated to assure that the program can be effectively carried out within existing budget limitations.

IV. HCFA should encourage:

* States without specific State regulations on the training of home health aides to develop a curriculum for training home health aides, or adopt an existing curriculum. Completion of an established training program should be a prerequisite for a home health aide position.

* Organizations such as the National Homecaring Council, National Association For Home Care and the Joint Commission on the Accreditation of Hospitals to work with their members to improve home health aide services through more effective training and supervision.

V. HCFA should revise those sections in the Health Insurance Manual for home health agencies and fiscal intermediaries (FI's) which deal with services provided by home health aides. The revisions should distinguish between personal care services and those services representing extensions of skilled care, indicating that all tasks in the plans of care are expected to be performed by aides during each visit.

VI. HCFA should revise the Home Health Agency Coverage Compliance Review instructions to P.I.'s. Revised instructions should expand the points to be addressed by P.I.'s
during onsite reviews to include comparison of aide tasks specified in plans of care with aide tasks performed, to assure that plans of care tasks for aides are fully implemented.

VII. HCFA should review home health aide services provided under a contract to determine whether a limitation on such services would be appropriate, in view of the findings that aides under contract:

* did not perform the majority of extensions of skilled care tasks assigned to them;
* subjected Medicare patients to substandard practices;
* made visits which were unnecessarily time consuming, frequent and costly.

APPENDIX I

HIGHLIGHTED HISTORY OF EARLIER INTEREST IN HOME HEALTH ISSUES

In 1981, studies of home health services under Medicare by GAO and HCFA included findings and recommendations related to home health aide services. GAO found that the use of aide services to assist beneficiaries with personal care could be reduced because the beneficiary or family and friends often could and would have provided the care required. HCFA identified overutilization of home health aide services resulting from Medicare fiscal intermediary misinterpretation of utilization policy.

Legislative changes in Section 1861(m)(4) of the Social Security Act in 1981 required home health aides to have "successfully completed a training program approved by the Secretary." HCFA drafted a regulation which established a training curriculum to meet the intent of law. That regulation was never finalized and no training standard was established.

On October 19, 1981, the Senate Permanent Subcommittee of Investigations, chaired by Senator William Roth, followed an investigation into home health services with a report. Responding to concerns about home health agencies' practices in providing many services under contractual arrangements the Subcommittee recommended that nursing services and one other service be provided only by employees of the agencies. This recommendation was made to alleviate questionable circumstances under which many agencies, characterized as "brokerage houses" by the Subcommittee, had been providing services.

In 1982, HCFA advised the Subcommittee that its recommendation would be reviewed. At the request of then HCFA Administrator Davis, regulations were drafted addressing the Subcommittee's concerns as well as others HCFA had about the Conditions of Participation for home health agencies. Those regulations were never finalized, and home health agencies are still permitted to provide many skilled and home health aide services under contract.

At recent hearings on "Home Care Quality" held by the House Select Committee on Aging, testimony was presented which highlighted a number of issues addressed in this report. The Committee also released a report prepared by the American Bar Association, entitled "The Black Box of Home Care Quality", which addresses quality standards and systems for monitoring the quality of care provided under Federal and State Programs. The Chairman of the House Select Committee on Aging, Representative Edward R. Roybal, sponsored a bill to address home care quality problems the Committee has identified. Among the reforms in the bill are "administrative and judicial sanctions" for quality assurance violations; the establishment by DHHS of "training requirements for all individuals delivering home care services"; and the development of "certification requirements for homemakers, home health aides and personal care attendants."
APPENDIX II
PROFILE OF REVIEW AND METHODOLOGY

The inspection included onsite visits in seven States (California, Connecticut, Illinois, New York, Pennsylvania, Tennessee and Texas) to 16 selected Medicare certified home health agencies (HHA's). Visits were also made in three of those States to nine aide vendor agencies with whom six of the 16 HHA's contract for aide services. Discussions were held with 194 respondents in these States and in five other States (Colorado, Iowa, Michigan, Minnesota and Ohio). Information on State standards was also provided by Florida, Iowa, Louisiana, Oregon and Virginia.

The 16 HHA's consisted of 12 voluntary agencies, including three hospital-based, and four proprietary organizations. Three agencies primarily serve urban areas, while two serve suburban areas; seven serve urban/suburban areas; three serve urban/suburban/rural areas; and one a rural area. The nine vendors are primarily located in urban/suburban areas of three Eastern States and one Southern State.

Respondents included HHA and vendor administrative personnel, State surveyors and licensure personnel, supervisory visiting nurses, home health aides, Medicare patients, physicians, and representatives of labor unions, educational institutions and home care industry agencies. A total of 62 Medicare patients and 44 home health aides were visited in the patients' homes.

Medical records from each HHA were obtained and reviewed by skilled medical professionals on the inspection team. The records corresponded to active and discharged Medicare cases selected onsite. Three active patients per agency were selected for a home visit at a time when their home health aide was present. A discharged patient from each agency was also visited at home, where possible.

The remaining data included agency policies and procedures concerning home health aides; personnel records of aides interviewed; contracts with vendors providing aide services; labor union agreements; State laws and regulations and other standards concerning aides; and training curricula from State agencies and public and private educational institutions.
APPENDIX III

EFFECTIVE STATE STANDARDS

The following State standards are drawn from the 11 States in the inspection sample which have regulations for home health aide services. These standards are recognized by the inspection team as being effective in helping to assure that home health aides are capable of providing the highest quality services to Medicare patients.

Recruitment and Hiring

Trainees receive pay

The State of Connecticut requires agencies to hire prospective home health aides before classroom training begins. The agencies must provide aides with 10 hours of orientation to the agency. During the orientation and 60 hours of classroom training, agencies must pay the prospective aides minimum wage.

Training

Prior approval of training programs

Seven States require prior approval of training programs for home health aides: California, Connecticut, Illinois, Iowa, New York, Oregon and Texas.

Clinical experience required in training programs

Five States' training standards require a minimum of from 15 to 30 hours clinical experience before training is considered complete: California, Iowa, New York, Texas and Virginia. In New York, a graduate of classroom training is not deemed qualified to practice as a home health aide until clinical experience is completed. In California, home health aides do not qualify for State certification (attesting to successful completion of training) until all training requirements, including clinical experience, have been met.

Uniform statewide system for training

The State of Connecticut requires that all approved training programs for home health aides are conducted by the State Department of Education, Bureau of Vocational Technical Schools or the Regional Community College program coordinated by the Matatuck Community College.
The CHAIRMAN. Well, Mr. Nicholson, I think your draft report is a rather startling report, and one that perhaps does a great public service in showing to the committee, the Congress, the public, and indeed HCFA itself, what is necessary to correct the circumstances where abuses at home where lack of care endanger patients lives and overall where the situation is intolerable.

Now, as I understand your draft report, you make no bones about it that HCFA should have drafted some regulations and had them in effect since about 1980 or 1981 on training, requirements, and standards for home health care aides.

Mr. NICHOLSON. Yes, sir.

The CHAIRMAN. Did you find out who deliberately or under what circumstances they neglected to do this?

Mr. NICHOLSON. Quite honestly, Senator Melcher, I am not clear on that. I understand though, on the basis of information obtained by my staff in the course of doing the study, that these regulations were in draft form as early as 1982-83.

The CHAIRMAN. And somehow were withdrawn?

Mr. NICHOLSON. Somehow never made it through the process to be published in the Federal Register, yes, sir.

The CHAIRMAN. They just disappeared, as if they had been shredded? [Laughter.]

Mr. NICHOLSON. I guess, yes, sir.

The CHAIRMAN. You know, it seems most peculiar that we can't get an answer on that, and I think we are going to pursue it a little bit further to find out exactly why they started to follow the law and draft the regulations and then just dropped them as if they had evaporated.

Did you hear Mr. Hays say this morning that the regulations were in place in regard to nurses, registered nurses?

Mr. NICHOLSON. Yes, sir, I did.

The CHAIRMAN. Did anything in your investigation explain why the regulations, if they are in place, are of such nature that a nurse can be told to meet an ambulance but not told what equipment would be necessary, what the procedures would be? Are the regulations that bad?

Mr. NICHOLSON. I think the regulations are probably fairly general, even with regard to the kinds of requirements set out for registered nurses or physical therapists or occupational therapists or other kinds of skills that are rendered in services through home health agencies.

It seemed to me that what happened in that particular instance with regard to that story as it was being told was obviously totally inappropriate, but I'll bet you that the regulations as they are laid out probably wouldn't cover anything as detailed as that. I mean, I imagine that the regulations underlying the law kind of contemplate that if the home health agency is being competently administered, that those kinds of situations could not or should not occur.

The CHAIRMAN. Well, I get the impression from all of our witnesses this morning that you find out it's all wrong, it's all haywire, nothing is set up, nothing would work unless you improvised, or reformed the system.

But in all this testimony, the point that is so discouraging is that nobody is in charge. There is nobody actually responsible to set reg-
ulations, that would force aides and nurses to know how to operate the equipment they might have to operate, and to use even whatever it is, whether it's a thermometer or a catheter or a pulmonary machine or a resuscitation machine, whatever.

In this morning's testimony, there wasn't anybody that shed a light on who would be in charge. And indeed the only conclusion we could reach was that nobody was in charge. Now, isn't that the most important thing that the regulations must set? How do you have regulations unless you have somebody on top that says, "Here's who is in charge. They are responsible. This outfit is responsible, this person, or whatever," and then go down below that? Shouldn't the regulations start that way?

Mr. NICHOLSON. It seems to me they probably should. I wouldn't claim to have the same level of expertise as the people that work in the Health Care Financing Administration probably do with regard to that issue. But as I understand it, yes, the regulations—which another name for those are "the conditions of participation"—represent the policies that need to be articulated by the Health Care Financing Administration and then the State survey agencies under contract with the Health Care Financing Administration have the responsibility to ensure that these regulations are in force.

I think perhaps a product of some of the problems might be money. I thought I heard Mr. Hays say that something like 50 percent more than had been provided previously would be added to the certification process. But in my judgment, at least, with regard to the Medicare home health agencies, that seems to be the key.

We did find, for example, even though home health agencies are supposed to be recertified once a year, that some had been backlogged for as long as 4 years, 3 years. It was not at all uncommon for the home health agencies to be surveyed only every other year as opposed to once a year.

The CHAIRMAN. Well, Congress wrote a law in 1980 and followed up in 1981, and I think the intent of the law was clear, and should have been carried out by having somebody in charge, some regulations in place to try to avoid all of the uncertainties, all the mismanagement and all the abuse that the witnesses exemplified this morning. So maybe Congress did the right thing.

Now, we also have a responsibility of oversight, and what we should have been doing since 1980 and 1981 is holding somebody accountable, because this testimony I judge was truthful—and fairly representative, too, by the way. I mean some of the patients were extreme cases, but I think the testimony was representative of what happens over and over and over with home health care.

I think maybe just talking about mid-level authorities here at HCFA, what we are sort of skirting around is: Who was responsible for writing that regulation? It's the Secretary. The Secretary is responsible. There has been dereliction of duty here, and it is something the Secretary cannot duck. Now, whether he knows it or not is beside the question. Whether he has people under him that should have been telling him that he doesn't have a regulation, that is beside the question. He is responsible to carry out, as Congress directs, in writing the regulations. He failed. Dr. Bowen, I
know, wasn't the Secretary in 1980. I am not sure, when was Dr. Bowen appointed, in 1981?

Mr. Nicholson. About a year and a half ago.

The Chairman. About in 1983. So it is not that he personally is responsible, except when he was sworn in. So somebody ahead of him didn't do the right thing at the right time, but he is still responsible now.

This dereliction of duty has to be ended. That is only part of the problem in getting the regulations drafted and in place. The real problem is going to be making them work.

I think you have done a great job here in your investigation. I commend you for that. I think you have stirred up not just HCFA and maybe Secretary Bowen, but you also have stirred up this committee and Congress to do something to assure the problem is solved.

I recognize regulations are just paper, just words on paper. It is the will and the spirit that will make this work, and I think that it's part of our oversight responsibility on this committee to assure that the will and spirit is there. I think you have given us a guideline on where to start and what to do, and I appreciate that very much.

Mr. Nicholson. Thank you.

Senator Burdick is here.

Did you want to ask questions of this inspector general, Senator?

STATEMENT OF SENATOR QUENTIN BURDICK

Senator Burdick. No questions, Mr. Chairman. But I will read your interrogations very carefully.

The Chairman. He declines to ask you any questions now, Mr. Nicholson, but thank you very much.

Mr. Nicholson. Thank you, sir.

The Chairman. Now Senator Burdick is going to replace me for a while here while I catch up on some of my other duties, and the committee will now hear from Ms. Jane Anderson. Jane Anderson is from Montana. She is a second part of this team of witnesses, and you will find that Jane, who has worked over in western Montana for a number of years, really knows her stuff.

Senator Burdick. Is she close to the North Dakota border?

[Laughter.]

The Chairman. No. She is a long ways from the North Dakota border. But you are going to find that she really lays it out as it is, and she has done marvelous work for years in Anaconda and the aging district over in southwestern Montana.

Senator Burdick [presiding]. Will Ann Mootz and Jane Anderson please approach the witness table?

You may proceed in any manner you wish.

STATEMENT OF ANN MOOTZ, FORMER DIRECTOR, HOME AIDE SERVICE AND UNITED HOME CARE, CINCINNATI, OH; TESTIFYING ON BEHALF OF NATIONAL ASSOCIATION OF HOME CARE

Ms. Mootz. Senator Burdick, I guess if I had Senator Glenn here to stick up for our people in Ohio, that would be a help. I am sorry he can't be here.
At any rate, I am here today representing the National Association of Home Care, NAHC. I come from a background of 20 years of being the director of one of the good home care agencies in Cincinnati and also from a 15-year background working with standards committees, accreditation committees, and quality assurance committees both in the National Home Caring Council and at NAHC.

I must say that 15 years ago, when some of us were working hard to get people interested in standards and quality care, it was a very lonely business. So it is very comforting to be here today and see so much interest in the subject and to see real leaders in the Senate committed to that purpose.

NAHC, as you perhaps know, is the largest professional organization representing the interests of home health agencies, homemaker-health aide organizations, and hospices. It has approximately 5,000 members. We in the home care field are very pleased to participate in this effort to focus on the issues of quality care.

Now, many of the concerns that we have have already been expressed this morning, and you do have our detailed testimony. So I would, if it's all right with you, like to mention the concerns briefly and then concentrate perhaps on our recommendations for dealing with some of the problems.

There, of course, has been a growing demand for home care services. Some of that relates to the easing of Medicare eligibility requirements, to the impact of the hospital DRG's and to just the demographic factors. When we were preparing for this testimony, it's pretty common knowledge that we expect 20 percent of our population perhaps in the year 2030 to be 65 or older, but I was very surprised to see that in 1900 only 4 percent of our population was 65 or older. So it has just been a tremendous growth in older people, who usually require care.

Unfortunately, we haven't used those very obvious demographic facts to prepare for the problems that we have and we are going to have in a much larger degree very, very soon.

Some of our concerns, relate to the administrative reductions in Medicare benefits. The interpretation of intermittent care, the interpretation of homebound has been done in such a way by the intermediaries and with the support of HCFA that many people who have previously been eligible are no longer eligible.

One of the key concerns about the Medicare program that we wanted to talk about was the lack of requirements for training of home health aides in that program. Now, I don't know if Mr. Hays has solved that problem this morning or not, but it is the first time that I had ever heard that this might be required under the Medicare Act. There are no requirements at the present time for training of the home health aides under either Medicare or Medicaid.

This sort of diminishing of the benefits in Medicare has increased the pressures on the social services block grants on Title III of the Older Americans Act to pick up the needs of this older population and a lot of younger disabled people. These programs, unfortunately, are plagued with fragmentation of service eligibility, coverage reimbursement, and standards.

I could just tell you that in our agency, United Home Care in Cincinnati, we had 30 different kinds of funding for home care.
With that many people monitoring us each year, with about six different financial auditors coming in each year, and still people fell through the cracks. We were taking care of 2,500 people a week, and yet there were always 300 or 400 hundred people on our waiting list for whom there were no funds available or who just simply didn’t fit the eligibility requirements of all these programs.

So really I don’t think we can talk about a home health system. We don’t have one in this country. What we have is a bunch of fragmented, very, very different kinds of programs, and many, many people, very needy people of all ages—infants, injured, paraplegic kids trying to go through college, young adults, and the older people—just simply fall through the cracks, for many reasons.

What is the current status then of our Federal program? I guess the most uniform quality control program we have at this point is Medicare. The standards under the Medicare conditions of participation are the minimum, which Medicare certify that the home care agencies must meet. The Medicare standards are generally appropriate. I think they have held up well over the years. But they do not, as we have said before, specify specific training or supervision of the health aides.

The other federally funded programs—social service block grant and the Older Americans Act—have no standards written in at all and they do not have conditions of participation which contain uniform standards. Instead, they just utilize many, many different State requirements and State levels of standards. And in fact, some States have almost none.

Many States—perhaps I shouldn’t say that, because I can’t give you the exact number—but some States rely on low bidders to be awarded the contracts. And others have written standards but have inadequate staff to monitor them. About 4 years ago, for instance, in Ohio we had two nurses in the whole State of Ohio to monitor certified home health agencies.

Particular problems I think that we have discussed many, many times today are with the use of paraprofessionals in all these programs, in the Medicare or the Medicaid, the social service and the aging programs. The fundamental problem, of course, is the lack of consistent standards for these paraprofessionals in all of them, and the fact that there are no requirements for training and for supervision.

Another problem is, of course, that we call these people all sorts of different things, so that it’s very hard to write standards for them. We call them “home health aides” in the Medicare program. We call them “attendants” in the aging program often. Individual providers—Europe is pretty smart, they just call them “home helps,” and we know what they’re talking about. But in our country we have many names, and it makes it really additionally difficult to monitor them.

We are particularly concerned, as we said, about the training and supervision of these paraprofessionals. To deal with that problem, you may know that the National Home Caring Council has promulgated national standards for homemaker/home health aide services, and it has administered an accreditation program since 1962.
The National League of Nursing and the Joint Commission of Accreditation of Hospitals also accredit home health care programs in some community agencies and hospitals. Such accreditation or approval is entirely voluntary and affects only a minority of home care agencies. For instance, I think one of those national groups has 135 agencies accredited and the other one has about 110. So you can see, of whatever it is, 6,000, 7,000 home care agencies in this country, that is a very, very small group. However, the standards that are written for those groups are very valuable, I think, as models for some possible Federal legislation.

The National Homecaring Council also developed under contract with the U.S. Public Health Service in 1978 model curriculum and teaching guide for the instructions of homemaker/home health aides.

Thus there are already certain basic standards written and curricula for training already established, and I think it might be interesting if Mr. Hays looked at some of that.

In June 1985 the Rensselaer County, NY, long-term care coordinating committee issued a report which recommended increased use of home health aides and personal care aide services. That report noted there are several reasons why personal care is not a highly desirable career path: Wages are low, the work environment is variable and often undesirable; work hours are not generally guaranteed; transportation costs are generally not covered for the worker; and consumers are often unclear about the worker's role and what they can ask someone to do.

Public recognition of the value of such a position is nonexistent. Homemaker and personal care service is a low-status, low-prestige, low-ceiling occupation. Keeping this in mind then, why should anyone want to perform those services well?

Clearly, much needs to be done to attract and retain paraprofessionals, but the quality of paraprofessionals could be enhanced by more adequate reimbursement for their services.

We would propose some of these standards for paraprofessional people in the home health services. We would suggest that home care services offered in federally funded programs have uniform conditions of participation and that paraprofessional salaries and fringe benefits should be increased. The conditions of participation which we propose would apply to all the programs, including Medicare and Medicaid, social service block grants, and Older Americans Act and so on.

Under such conditions, these Federal programs would be required to have, first of all, a consistent job title for the paraprofessional; two, basic training requirements, and you could then upon the basis of the original training develop specialties, special training in caring, for instance, for Alzheimer's patients, for caring for infants who need special care and using high-tech equipment; three, basic common supervision and monitoring requirements with the States required to fix the responsibility for this and to accept the responsibility for it; and last, basic benefits, wage policies, and safeguards for the person who provides this vitally important service.

Until there are federally mandated standards, State licensure programs are the only means for ensuring standards. Present State
licensure laws, however, present a crazy-quilt of who is regulated, who is protected, and from what. I think currently there are about 36 States that have a form of licensure law. Some are effective and some are not. Perhaps then the Federal Government might want to develop a model licensure law which could be used by the States to make their programs more effective.

One of the big problems with the use of paraprofessionals, I think, while many of them were very obvious this morning in the testimony—Mrs. Tolbert, for instance, talked about her attendants—we call them sometimes "self-providers." Using individuals as providers who are not employed by agencies is a very, very serious problem.

Some States subcontract directly with individuals to provide nursing and homemaker/health aide services instead of obtaining these services through an agency. Some area agencies on aging or States through Medicaid or the social service block grants are currently hiring case managers who, while they are not providing direct patient care, are brokering the provision of home care and supportive services.

The problem is that some case managers are hiring or contracting with individuals directly to provide services instead of dealing through agencies, meeting recognized standards in the home care field. In some cases, the result has been a lack of training, poor, if any, supervision, and some examples of poor care and abuse, which we certainly did hear about this morning.

A related problem is the method by which some area agencies on aging in the States contract out for home care services under the social service block grant or Title III. Contracts are placed out for bid, and the lowest-cost provider is chosen. Accredited and certified agencies, which have the cost of training and supervision, simply cannot then compete with those who don't. The result is that underqualified and undersupervised individuals are being chosen to render care under these titles. We would hope that that could also be stopped by federally mandated standards.

In conclusion, while we are very proud of most of the home care services that are being given, we certainly wish to suggest some ways in which the quality of care could be improved. We would then recommend that uniform conditions of participation, particularly training and supervision standards, be mandated for all Federally funded programs utilizing paraprofessionals, or that training requirements based on the model curriculum should be included in the OAA and social service block grant legislation.

We would recommend increased reimbursement for paraprofessional services, common definitions that would make the programs easier for the public to understand and for the Government to monitor; and development of a model licensure law that might help the States be more effective.

Last, the prohibition of independent employment of paraprofessionals using Federal funds would greatly improve the quality of care that is being given now.

We certainly support—would hope the Congress would enact really—S. 1076, the Medicare Home Health Care Services Improvement Act of 1987. This would greatly clarify the home health care
benefits so that beneficiaries would receive the service they need, and it would increase the general quality of care.

I would be glad to try to respond to any of your questions.

[The prepared statement of Ms. Mootz follows:]
TESTIMONY OF

ANN MOOTZ
FORMER DIRECTOR OF HOME
AIDE SERVICE AND UNITED HOME CARE

CINCINNATI, OHIO

REPRESENTING

THE NATIONAL ASSOCIATION
FOR HOME CARE

before the

SENATE SPECIAL COMMITTEE ON AGING

April 27, 1987

Mr. Chairman and Committee Members:

I am Ann Mootz, here representing the National Association for Home Care (NAHC). For the past 20 years, I was Director of Home Aide Service and United Home Care in Cincinnati until retiring this past January. I sat on the Board of Directors of the National Homecaring Council for 15 years and chaired their Accreditation Committee for 5 years. I have served as a member of the NAHC Quality Assurance Committee and currently serve on the National Homecaring Council Advisory Board.

NAHC is the largest professional organization representing the interests of home health agencies, homemaker-home health aide organizations and hospices with approximately 5,000 members. NAHC is committed to assuring the availability of humane, cost-effective, high quality home care services to all who require them.

We in the home care field are pleased to participate in this effort to focus on the issue of quality of services and problems with the delivery of home care. The issue of quality is critical to what we do and what we are all about. Home care services are provided behind closed doors in private homes, to millions of people who by definition are the vulnerable members of our society due to their inability to care for themselves. The care is rendered in a setting which is not subject to public scrutiny. The very nature of the services places unique responsibilities on providers of care.
OVERVIEW OF QUALITY OF HOME CARE

We are proud of a record of outstanding service to the ill, elderly, and disabled in this country. Home care in the U.S. traces its origins back to 1885, with Visiting Nurse Associations across the country springing up to provide health care to an influx of immigrants. Home health was accepted as part of the Medicare program in 1965, and became more available to millions of elderly and disabled Americans. In its 101 year history, home care has enjoyed ever growing support, and a largely unblemished reputation. The vast majority of patients have been very pleased with the services they received, and the quality of those services. In the entire history of Medicare and Medicaid since their enactment in 1965, there have been less than a dozen convictions of home care providers for fraud. This is too many, but is an enviable record compared to the literally thousands of other providers in various categories of health care who have been convicted.

Home care has been free of quality problems for many reasons, one of which is that the field was comparatively small. Now, however, there is a growing appreciation and demand for home care. The rapid growth of the industry can be traced to an easing of eligibility requirements under the Medicare law and to the impact of hospital prospective payment system as well as demographic factors.

This increased demand has come at a time when access to the home health benefit under Medicare is being limited.

ADMINISTRATIVE REDUCTION IN THE MEDICARE HOME HEALTH BENEFIT

Recent policies of the Health Care Financing Administration (HCFA) to restrain beneficiary protections, combined with vague and confusing guidelines for providers, result in reduced access to home health care for Older Americans’, according to a July, 1986, report by your own Committee.

The report noted that although hospital discharges to home health have increased 37 percent since prospective payment for hospitals was implemented, the growth in home health services since then has slowed. A 1987 General Accounting Office survey of hospital discharge planners revealed that 86 percent “reported problems with home health care placements” for Medicare beneficiaries. 52 percent of those surveyed cited “Medicare program rules and regulations” as “the most important barrier” to these placements. It is no coincidence that HCFA’s own statistics show that the percentage of home health claims denied under the Medicare program rose from 1.2 percent in 1983 to over 8.0 percent in 1988. And this figure does not include the many patients who are effectively denied Medicare coverage because home health agencies, incapable of assuming the costs of non-covered care, avoid Medicare claims submissions.

The present HCFA guidelines allow for daily visits for a two to three week period, and thereafter, visits may be continued upon a showing of exceptional circumstances. This level of services is often inadequate to care for more acutely ill patients who are being discharged from hospitals.

In addition, definitions of what constitutes “intermittent care” vary tremendously, depending on the fiscal intermediary’s (FIs) interpretation. As a result, Medicare, which is supposed to be a national program, is not enforced uniformly, and what is covered for one beneficiary in one state is not covered in other state.

A related practice, known as “selective billing,” has served to further restrict home care coverage for Medicare beneficiaries. If patients are receiving coverage under Medicare, in many cases they cannot receive additional coverage from Medicaid or any other payment source (private insurance, self-pay, Social Services Block Grant, etc.). For example, if patient A is receiving 3 hours of nursing care and 2 hours of aide care for 3 days a week paid for by Medicare, and he or his family wants an additional 2 hours of nursing care on the other 2 days which will be paid by concerned relatives, Medicare intermediaries will deny the Medicare coverage, claiming that the patient is exceeding the “intermittent care” requirement. This either will result in no care, limited care, or the forced institutionalization of an individual whose family cannot sustain him at home if Medicare refuses to pay its fair share.

The Medicare homebound guideline allows the patient to be considered homebound if he has infrequent or short duration absences from the home primarily for medical treatment or “occasional non-medical purposes” (e.g., trip to barber, a drive, walk around the block).
The current definition in the guidelines is interpreted in an inconsistent and varying manner by fiscal intermediaries. This is especially so in cases where beneficiaries are leaving their homes to go out for periodic adult day care, outpatient kidney dialysis, chemotherapy and other similar treatment. Even though the current guideline allows beneficiaries to go out for medical reasons, some FIs severely limit frequency and others do not honor the medical reason exception at all. In situations where individuals leave their homes for either medical or non-medical reasons, individual FIs have their own interpretations as to what they consider frequent or infrequent, or whether they consider the patient homebound if he or she leaves home with the aid of an ambulance or other extraordinary assistance.

This ratcheting down of the Medicare home health benefit has increased the demand for services under Social Services Block Grant and Title III (the Older Americans Act). These programs are plagued with fragmentation of services eligibility, coverage, reimbursement, and standards, which, when combined with the burgeoning demand, fosters the potential for decreased quality in home care services.

The home care community has no more vital interest at the present time than to ensure the high quality of service. That is why I am delighted to be here with you today, to discuss with you a few areas in which problems occur and will escalate. I also plan to make recommendations for improvements in those areas.

CURRENT STATUS OF FEDERAL PROGRAMS

The most important uniform quality controls for home health agencies are the federal "Medicare Conditions of Participation". These standards, which apply to some 5,000 home health agencies certified for participation in the Medicare program, set forth basic standards for organization, services, administration, professional personnel, acceptance of patients, plans of treatment, medical supervision, skilled nursing services, therapy services, medical social services, home health aide services, clinical records, and evaluation. These standards are the minimum with which Medicare-certified home health agencies must comply; several states require higher standards in some areas. The Medicare standards are generally appropriate and reasonable, but they do not specify a particular method for meeting training and supervision requirements for home health aides.

The other federally financed programs (Medicaid, Social Services Block Grants to states, and the Older Americans Act), do not have conditions of participation which contain uniform standards for home care services. Instead, the programs utilize standards devised by various state or local governments, some of which are extremely minimal or absent. Others have no standards, but simply rely on the lowest unit price bidder to provide these services. Others have written standards, but have inadequate staff to monitor and enforce them.

PROBLEM AREAS IN PARAPROFESSIONAL SERVICES

As you can imagine, a fundamental problem in these federal programs is a lack of consistent basic standards for paraprofessionals. The home health aide side of the Medicare program is essentially doing the same tasks as the homemaker of the Social Services Block Grant program, the same tasks as the personal care side of the Medicaid program, and the same tasks as the home aide in some programs for the aging, those with mental illness, or people who are developmentally disabled. The various titles used to designate the home care worker reflect various funding sources, not actual tasks. The paraprofessional function is the same: to provide appropriate supportive services to persons in their homes under the proper professional supervision and in accordance with a plan of care. But the programs lack minimum mandatory supervision and training requirements for homemaker-home health aides.

We are particularly concerned about training and supervision requirements for homemaker-home health aides and other paraprofessionals. The issue of standards for paraprofessionals in home care is not new. To deal with the problem, the National Homecaring Council has promulgated national standards for homemaker-home health aide services, and has administered an accreditation and approval program based on those standards since 1962. (Accreditation requires a site visit, while approval requires only a self-study and other written materials). The standards cover agency structure, staffing, training, supervision, service, and community relations. The National League for Nursing and the Joint Commission on Accreditation of Hospitals also accredit home health programs provided through some community agencies and hospitals. Such accreditation or approval is entirely voluntary, however, and only a minority of home care agencies in the country are accredited or approved.

The National Homecaring Council also developed, under contract to the U.S. Public Health Service, a model curriculum and teaching guide for the instruction of the homemaker-home health aide in 1978. This curriculum has been updated and is now in its third printing (1984). This 60-hour training program is referred to in the
Federal home health agency expansion and training grants administered by the Public Health Service. Thus, certain basic standards and curricula already exist, but are simply not used in many federal and state programs.

It is ironic that standards and training curricula are established for individuals who are professionally trained and licensed, such as physicians and nurses, while there are no uniform standards for paraprofessionals, often with less formal education.

The individuals providing these paraprofessional services are, in large majority, sincere, dedicated and hardworking people who are underpaid in relation to the value of the work they do. Few have paid vacations or holidays, and even fewer have paid health insurance coverage. We have not given adequate attention or recognition to the persons who provide this vital service; in fact, in many respects we have exploited them. We have sown seeds for a potential scandal. We have ignored the escalating human needs of paraprofessionals while we have continued to delegate more care to them, and to place more demands on them.

In June, 1985, the Rensselaer County (New York) long-term care coordinating committee, a group composed of representatives of home care providers, hospitals, nursing homes, health planners, and county government issued a report which recommended increased use of home health aides and personal care aides services, based on enhancement of the labor pool. The report noted that "homemaker/personal care has been a difficult service to staff and maintain with a stable personnel pool over time. Within the last five years, this labor pool appears to have diminished even more. In light of demographic trends which indicate a growing need for this type of service, it is essential that the pool of workers be expanded and stabilized."

"Clearly, marketing is important in tackling this task. There are several reasons why personal care is not a highly desirable career path. Wages are low, the work environment variable, and often undesirable. Work hours are not generally guaranteed. Transportation from case to case is generally the worker's responsibility. Consumers are often unclear about the worker's role and responsibilities. Clients often demand inappropriate care. The collegial atmosphere in a contained work unit is absent, as caregiving is outsourced, resulting in lack of regular peer support. Public recognition of the value of such a position is non-existent. Homemaker/personal care service is a low status, low prestige, low ceiling occupation."

Keeping this in mind, why would anyone want to perform this function? (Enhancing Aide Service in the Home: Recommendations for Action, report of the Long Term Care Coordinating Committee, Rensselaer County, New York, 1985).

The report then went on to call for expansion of the personnel base by vigorous marketing and recruitment efforts, structured career paths, basic benefit packages, in-service training, and other actions which not only would attract and retain workers, but also give them a feeling of self worth and adequate pay for the work performed.

Clearly, much needs to be done to attract and retain paraprofessionals, but the quality of paraprofessionals could be enhanced by more adequate reimbursement for their services.

PROPOSED STANDARDS FOR PARAPROFESSIONAL SERVICES

In short, to improve the home care services offered in federally-funded programs, uniform conditions of participation should be developed and implemented, and paraprofessional salaries and fringe benefits should be increased.

The conditions of participation I propose would apply to all federally reimbursed programs providing paraprofessional home care services (Medicare, Medicaid, Social Services Block Grant, Older Americans Act, etc.). Under the conditions, these federal programs would be required to have:

1. Consistent job titles,
2. Basic training requirements, on which could be built additional training needed for specific programs or client groups,
3. Basic common supervision and monitoring requirements with states required to fix the locus of these and accept responsibility for them, and
4. Basic benefits, wage policies, and safeguards for the persons who provide this vitally important service.

In addition, reimbursement for services in the home should be allowed to increase in order to more adequately compensate for the value of the services these paraprofessionals are providing.
Until there are Federally-mandated standards, state licensure programs are our only means for ensuring standards. Present state licensure laws, however, present a crazy quilt of who is regulated, who is protected, and from what.

Currently, 36 states have some form of licensure laws covering home health agencies. There is no uniformity among these laws (and their implementing regulations). There is also no model licensure law (or regulations) to look to for guidance. Thus, in the states without a licensure law (and in many states with a licensure law) there is inadequate state regulation to ensure that home care agencies are fiscally stable and staffed and organized to ensure quality care. Certificate of Need (CON) laws do not provide a regulatory solution to assure quality and fiscal stability in lieu of licensure.

There should be a model law to provide states with guidance in developing a home care agency licensure law and regulations, and to ensure or enforce standards for persons providing homemaker-home health aide services. We would be happy to work with Congress to develop model licensure provisions to fill this gap.

**USE OF INDIVIDUALS AS PROVIDERS**

There is a serious problem when states subcontract directly with individuals to provide nursing and homemaker-home health aide services instead of obtaining these services through an agency. The approach of using individuals as providers has created problems where there has been insufficient training or supervision of the caregivers, with the result that the quality of care is often poor. Worse than that, there have been numerous examples of outright abuse of clients by caregivers. A recent incident in California illustrates how serious such abuse can be. There, an independent contractor aide was arrested and charged with arson, attempted murder, and fraud after she allegedly attempted to murder her client to cover up stealing nearly $5,000 from him during the year she had cared for him. We want to avert such dreadful incidents in the future.

The primary impediment to the states’ use of independent providers is that the Internal Revenue Service (IRS) views these individual providers (and property so) as employees of the state. This means that under present law, the states and counties are required to pay FICA, unemployment and worker’s compensation as well as withhold federal income tax on behalf of these individuals. In some instances, however, these payments on behalf of the employees are not made unless a challenge is brought against the state.

In addition, some Area Agencies on Aging (AAAs) and the states through Medicaid or the Social Services Block Grant program are currently hiring case managers who, while they are not providing direct patient care, are brokering the provision of home care and supportive services. The problem is that some case managers are hiring or contracting with individuals directly to provide services instead of dealing through agencies meeting recognized standards in the home care field, such as those established by Medicare certification. The National Homecaring Council, the National League for Nursing, or the Joint Commission on Accreditation of Hospitals. In some cases, the result has been a lack of training, poor, if any, supervision; and some examples of poor care and abuse. Again in these cases the agency brokering or assigning the worker should be responsible for adequate training and supervision, as well as for employee benefits.

A related problem is the method by which some Area Agencies on Aging and the states contract out for home care services under the Social Services Block Grant and Title III. Contracts are placed out for bid and the lowest cost provider is chosen. This method may be appropriate for bridges and roads, but is unsuitable and dangerous for home care and supportive services. Accredited and certified agencies cannot complete on a straight cost basis. The result is that under-qualified and under-supervised individuals are being chosen to render care under these titles. Contracts under block grants and Title III should be based not only on cost but also on required levels of training and supervision which should be specified in the contract.

**SUMMARY**

In conclusion, while we are proud of the services we provide to ill, disabled, and elderly Americans to maintain them in their homes, we would like to suggest some ways in which the quality of care could be improved. We recommend:

* Uniform conditions of participation or uniform training and supervision standards based on level of care need for all federally funded programs utilizing paraprofessionals; or training requirements based on the model curriculum should be included in OAA and Social Services Block Grant legislation;

* Increased reimbursement for paraprofessional services;
Common definitions which would make these programs easier for the public to understand and for the government to monitor;

Development of a model law and regulations for home care licensure; and

Prohibition of independent employment of paraprofessionals using federal funds.

In addition, Congress should enact S.1076, the Medicare Home Health Services Improvement Act of 1987, which would clarify the Medicare home health benefit so that beneficiaries receive the services they need. This bill, introduced by Senators Bradley and Mitchell, would:

- Clarify the definition of intermittent care to include one or more visits per day on a daily basis for up to 60 days and thereafter under exceptional circumstances. Daily care would be clarified to mean seven days per week;
- Codify the current homebound guideline and clarify that an individual need not be totally dependent and bedridden to be considered homebound;
- Improve the quality of care in a number of ways, including creating standards for training of paraprofessionals and a patient bill of rights for home care consumers.

Thank you for the opportunity to be here today to discuss these important issues with you. I will be happy to respond to any questions you may have.
The CHAIRMAN. Thank you very much.
Ms. Mootz, you have stated that the home care industry has experienced relatively few quality problems.
Ms. Mootz. I said that?
Senator BURDICK. In your written testimony?
Ms. Mootz. Oh, in detail. All right. After listening this morning, I would think that was a crazy thing to say.
Senator BURDICK. Well, I have to finish the sentence. While I would agree that most people are pleased with the care that they receive, I believe that the lack of reported problems could be attributed, at least in part, to the fact that these patients have no one to complain to. Do you agree with me? And how do you think we can give the consumers of these services a greater say in the care they receive?
Ms. Mootz. Well, many of the programs do not, for instance, give a role to the consumer in the first place. They do not ask for their opinions. They do not give them the right of appeal, and they certainly have no one person in the State to whom they can make their complaints. That would be a more effective way of doing it, and I think it's part of the quality assurance process that should be written into the use of Federal funds for all the programs. The consumer aspect of it is certainly very, very important.
Most good agencies send questionnaires to their consumers at least once a year. They certainly send a more detailed questionnaire to every case that is closed, because then the person isn't dependent on them any longer and can be more honest about the service. And they make a real effort to use consumer opinion to improve themselves. But it needs to be done in much more volume and by many more agencies.
Senator BURDICK. Despite your comments that most quality problems are generally confined to non-Medicare certified agencies, in 1986 a AARP report states that, "Consumers cannot assume that a Medicare-certified agency in fact operates up to the standards or that it provides high-quality care." How do you respond to this finding?
Ms. Mootz. Well, I think that that is true, for several reasons. One, that the States have not had the staff and the funds to monitor Medicare agencies adequately in the past. Secondly, of course, as we have said many times today, there is no requirement for training and supervision of health aides. Third, there are no detailed instructions about orienting and training nurses for new techniques and keeping them up to date, so that it is possible for an agency to be not giving top service even though they meet the standards as they are now written. I think that is one reason that the voluntary accreditation programs of NLN and the National Homecaring Council have been so valuable because they do require a higher standard of care.
Senator BURDICK. Well, what do we do when we find an institution that doesn't have an operation up to standards? What can we do?
Ms. Mootz. Well, I would hope that they would no longer be funded through any Federal program and that it would be enforced and that some civil penalties would also be used. We have been too easy on the home care people in the past.
Senator Burdick. That would require greater supervision than we have had today then?
Ms. MooTz. Yes.
Senator Burdick. We discussed the quality problems associated with some home care aides, the lack of proper training and supervision, low wages and little or no benefits and so forth. I am sure that everyone here would agree that these problems need to be addressed, but also that it will be expensive to implement.
Ms. MooTz. Right.
Senator Burdick. How can we be sure that the bulk of these costs will not be passed on to home care patients?
Ms. MooTz. Well, I think the bulk of costs is paid for by third parties. The costs will be passed on to the taxpayers. In our agency we estimated that training our home health aides—and we trained all of them—costs about 2 cents an hour, added 2 cents an hour to our cost of service. It was well worth it. You know, any kind of training, whether it’s nurses or physicians, is costly. But it’s a matter of whether it’s desirable and important. And this seems to be.

Senator Burdick. In other words, we have to pay for everything in some way.
Ms. MooTz. We have to pay for it. But it might be possible, by simplifying all these programs into one, to cut down a lot of administrative cost and to use some of that savings to help.

This morning we heard a lot about increase in home care, but it’s still only 3 percent of the Medicare Program. So it isn’t that we are overwhelming everyone.

Senator Burdick. Thank you very much.
Ms. Jane Anderson, you are next.

STATEMENT OF JANE ANDERSON, DIRECTOR, AREA V AREA AGENCY ON AGING, ANACONDA, MT; TESTIFYING ON BEHALF OF NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

Ms. Anderson. Senator Burdick, I am an area agency director in Anaconda, MT, and a member of the board of directors of the National Association of Area Agencies on Aging. The association represents the boards, advisory councils, service providers, and staff of over 670 area agencies on aging nationwide.

Area agencies on aging allocate approximately one-quarter of their funds nationwide to various types of home services, including homemaker, chore, personal care, respite, home-delivered meals, and nursing care. We are mandated to monitor and evaluate all programs and do so through a contractual relationship with community providers. To release funds, definitions of services and standards of performance are included to enable us to monitor their programs adequately. Thus, the area agencies on aging have been standardizing the Older Americans Act-funded programs but have no impact on home care programs not managed by the area agencies.

Most of our agencies have adopted our association’s taxonomy of services, a common definition of services nationwide. We do not at this time have a nationwide system of standards for the numerous
programs under the Older Americans Act, let alone the many other sources of funding supporting home care.

We commend the committee for conducting the hearing on this topic, standardization of in-home care. Standards for in-home care are necessary in the management of comprehensive local systems of care, providing community-based long-term care to the dependent elderly. The growth of in-home care services and providers, facilitated by recent changes in Medicare, is rapidly intensifying, and we can expect future demands for ever-increasing services driven by the population of the very old growing four times faster than the general older population.

New research conducted by the University of Texas Health Science Center in Dallas shows that the elderly's needs for home care and personal care service is two to three times the actual use of such services.

I would like to make two points during my testimony: Number one, NAAAA supports the call to develop standards for in-home services, keeping in mind the tenet that standards should not result in limiting needed care; two, the development of standards must result in home care being fully integrated into the local system of providing community-based long-term care.

My first point, NAAAA supports with qualifications the development and implementation of standards or community-based home care. Research has shown that as a result of the recently enacted DRG system, demand for Older Americans Act-supported in-home skilled nursing care has increased 196 percent, and the demand for housekeeping and personal care has increased over 60 percent, as the elderly are discharged from hospitals in a more frail condition. The demand and need for in-home care will continue to increase as a result of the DRG's current pent-up need and the growth of the frail population. In this growing market, national standards or, to phrase it another way, standardized products, are required by all concerned. No matter where a client or a caregiver lives, they have a right to know exactly what they are buying and receiving. Providers need a common language for planning, marketing, and delivery of services. Area agencies on aging need standardized assurances of quality and unit costs. Third-party payers need a standardized rationale for the actuarials necessary for the development of new products.

In this regard, policymakers have more or less surrendered the field of assuring community-based long-term care to the private sector. Insurance companies are interested in developing products for the long-term care market, but are wary of entering these uncharted waters. Comprehensive standards tied in with managed care would encourage the private sector to take on this new role.

Makers of public policy will have to come to the aid of the private sector if they want to address long-term care in a meaningful way. Standards, however, should not result in restricted access to care because of unavailability or costliness occasioned by the standards. Many area agencies on aging in rural areas, for example, have had to deal with a lack of providers and created ways to see that the frail elderly could remain in their own homes. In some instance, area agencies have had to create nonprofit providers to fill gaps in services.
This has been the case in my own hometown. There was no provider of home care services, so the area agency developed one to provide home health services. We are concerned that too-stringent standards, dealing perhaps only with criteria for personnel, may result in restricted access to needed care.

For instance, we do not believe that it is necessary for homemakers or chore service workers providing no physical care to be supervised by an R.N.

We at NAAAAA have data which proves that in-home care can be more cost effective than institutional care, but in order for efficiencies to result, we believe that care where possible is best planned, coordinated, and managed by an agency which has no monetary interest in the services provided.

This leads me to my second point. NAAAAA recommends that standards for in-home care integrate services with a system for comprehensive community-based long-term care established by the Older Americans Act. The outcome of standards should be quality, efficiency, and appropriate care. I don’t think anyone will disagree with these goals. To achieve these ends, however, we must integrate home care within the total package of community-based long-term care. If standards focus only on quality, then cost savings to both public and private payers and appropriateness are likely to suffer, both at the expense of the client as well as the home care industry.

Area agencies on aging regularly monitor their contracts with providers. The emphasis, however, of this effort is on contractual compliance. The contract is the focus of attention. This is the one result of the area agency fulfilling its mandate to monitor programs of the Older Americans Act.

Contractual monitoring, however, is not what the client needs. Clients need a quality package of care that can be brokered on their behalf. Clients need a managerial approach to care that focuses on them. Case and care management is this approach. Care managers working with the client in both the informal and formal support networks plan appropriate care, mixing and matching various resources for efficiency, see that the care is provided, and follow up to see if quality care has been rendered. Care management saves money.

Most people will not argue about the effect of care management on the quality of life of dependent persons. Certainly, remaining at home in the community is to be preferred, if at all possible, to residing in a nursing home. Some, however, may object to the care management and the provision of the continuum of care of community-based long-term care has not been proven to be cost effective. These people point to the evaluation of the long-term channeling projects funded by the Administration on Aging and the Health Care Financing Administration.

Research by our membership proves otherwise. In Maine, case management under the auspices of the area agency on aging, in addition to helping frail older persons remain in their own homes, has saved the taxpayer 54 percent of the cost of institutional living. Similar results are reported for Michigan and Oregon.

To summarize then, NAAAAA supports the development of national standards for in-home care, emphasizing the guiding princi-
ples that such standards ultimately cannot be so stringent as to result in limited access.

In addition, to ensure the goals of quality, efficiency, and appropriateness, NAAAA strongly recommends that the standards require the meaningful linkage of in-home care with area agencies on aging and care management, a care management system provided by an entity separate from the home care providing, thus avoiding possible conflict of interest. NAAAA offers to work with the committee on this task.

Thank you.
Senator BURDICK. Thank you.

As we have heard in testimony presented here today, there are serious difficulties in monitoring the quality of home care services. Among the roles mandated for area agencies by the Older Americans Act, as you mentioned, is the monitoring of services provided within their area of jurisdiction.

Do you believe area agencies should expand their monitoring beyond that which is contractual?

Ms. ANDERSON. Yes, I believe so.
Senator BURDICK. You mentioned in your testimony that clients need case managers. What kind of training do case managers receive?

Ms. ANDERSON. What kind of training do they receive?
Case managers are usually professional social workers or R.N.'s with a background of client care. And in our area we have an informal case management system. The case managers are the R.N.'s within the different counties, within the different hometowns and counties. They make themselves aware of the different programs that are offered within their area and see that their patient is referred to the proper referral source.

Senator BURDICK. Do you believe that this management assures home quality care is effective in providing it?

Ms. ANDERSON. Yes, I do.
Senator BURDICK. And much better care than if you didn't have them?

Ms. ANDERSON. Yes. I think that it provides for more monitoring of the different programs.
Senator BURDICK. What training do these managers receive? Do they have any medical training, or is it all business training?

Ms. ANDERSON. Within our area and within the State of Montana, most of the case managers are either social workers with a degree in social work or they are R.N.'s.
Senator BURDICK. Do you ever have any contact with Williston, ND?

Ms. ANDERSON. No, I did not.
Senator BURDICK. Too bad. [Laughter.]
That's my hometown.
Thank you very much.
Ms. ANDERSON. Thank you.
Senator BURDICK. The record will remain open for 10 days for such comments you care to file.
Until then, we will be in recess.
The committee is adjourned.
[Whereupon, at 3:12 p.m., the committee was adjourned.]
APPENDIXES

APPENDIX 1—MATERIAL RELATED TO HEARING

Item 1

April 29, 1987

TESTIMONY
OF EDWARD R. ROYBAL
BEFORE THE SENATE SPECIAL COMMITTEE ON AGING HEARING
"HOME CARE: THE AGONY OF INDIFFERENCE"
APRIL 27, 1987

I wish to commend the Senate Special Committee on Aging and you, Chairman Metzen, for holding this hearing on the issue of home care quality and the role of the Older Americans Act in assuring access to quality home care. The House Committee on Aging, which I chair, has drawn attention over the past year and a half to the inadequacies of our current system of quality assurance when it comes to home care.

Concern over the quality of home care is compounded by the rapid growth in the use of home care services by older persons, by the numbers and varieties of providers entering the home care market, by growing public and private investment in home care, and by the impact of recent cost containment measures on beneficiary access and home care quality.

The Congress' first extensive look at this issue was last July at the House Aging Committee's hearing, "The Black Box of Home Care Quality." At this hearing, we released the findings of the American Bar Associations (ABA) study of home care quality that outlines the lack of knowledge about the quality of care provided in the home setting and the inadequacy of our current quality assurance system.

As a result of the Committee's findings, I introduced H.R. 5669 in the 99th Congress and have reintroduced this session "The Homecare Quality Assurance Act of 1987" (HCCA), H.R. 1700. This legislative proposal comprehensively addresses many of the deficiencies in our current home care quality assurance system. The Act covers all "home health" and "home help" services provided to persons of all ages under Medicare, Medicaid, the Older Americans Act, and the Social Services Block Grant. I request, Mr. Chairman, that a summary of H.R. 1700 be included with my statement in the hearing record.

H.R. 1700 provides a starting point for debate on a number of home care quality issues — from consumer protection; to quality assurance standards, monitoring and enforcement; to research and training; to improved wages and benefits for home care workers. The Act would also create a new ombudsman service for home care consumers under the Older Americans Act, which is the focus of this hearing.

I am pleased to acknowledge the attention that has already been given to H.R. 1700 in several other legislative tracks. First, Senator Barbara Mikulski will shortly introduce a Senate companion bill to H.R. 1700. Furthermore, many of the Medicare provisions of H.R. 1700 are also included in and supported by companion legislation to be shortly introduced by Senator John Bradley and by Congressman Henry Waxman.

Of particular relevance to this hearing is the reauthorization of the Older Americans Act this year. This provides the opportunity to strengthen the role of the state ombudsman program to include advocacy on behalf of home care consumers as well as residents of nursing home and board and care facilities.

The Administration's interest in home care quality is also evident in their consideration of home care quality demonstration projects, improved survey procedures and deemed status for accredited home health providers.

I encourage and remain personally committed to continued Congressional support and legislative action to ensure that all care provided in the home is of the highest quality possible and delivered in the best interests of consumers and their families. I therefore appreciate this opportunity to address this Committee and look forward to our continued, cooperative efforts in the future.
EDWARD R. ROYBAL
Chairman, House Select Committee on Aging

"THE HOMECARE QUALITY ASSURANCE ACT OF 1987 (HCOA)"
H.R. 1700

March 1987
Contact: (202) 226-3375

PURPOSE: "The Homecare Quality Assurance Act of 1987" (HCOA) is designed to promote the health, safety and well-being of persons receiving health and supportive services in their home under Medicare, Medicaid, the Social Services Block Grant, and the Older Americans Act. HCOA offers a comprehensive approach to ensuring the quality of homecare services by improving consumer protections, by addressing the serious deficiencies of our current quality assurance system when it comes to care provided in the home, and by increasing research and training in home care quality.

THE ISSUE: With the rapid increase in the number of older persons and need for health and support services, the number of homecare providers and proprietary agencies, in particular, have mushroomed over the past two decades with virtually no provisions to ensure the quality of care delivered. Little is known about the quality of care provided in the home, who is providing services, how many people are being served, and what public and private dollars are being expended. Most importantly, the in-home location of services makes the actual delivery virtually invisible and, therefore, largely beyond the reach of public or professional scrutiny.

BILL PROVISIONS

* Establishes a federal bill of rights for homecare consumers under Medicare, Medicaid, the Social Services Block Grant, and the Older Americans Act.

* Sets "home health" and "home help" quality assurance standards and requires agency compliance as a condition of participation under Medicare, Medicaid, the Social Services Block Grant, and the Older Americans Act.

* Requires that homecare agencies have plan of care policies that identify services to be provided, have a means for identifying additional client needs, and coordinate with other service agencies.

* Requires that homecare agencies have appropriate administrative policies including governance structures, fiscal and personnel management, and client records.

* Requires that PROs conduct quality assurance monitoring of all home health agencies funded under Medicare or Medicaid. Requires that states have a quality assurance monitoring mechanism for home help services funded under the Social Services Block Grant, the Older Americans Act, and the Medicaid Home and Community Based Services Waiver Program.

* Amends the Older Americans Act to include and provide separate funding for homecare ombudsman activities for the purpose of investigating and resolving homecare as well as nursing home and board and care complaints.

* Requires federal survey of homecare agencies with allowances for "deemed status" for agencies accredited by organizations certified by states having standards at least as stringent as the federal conditions of participation.

* Encourages states to establish comparable quality standards and survey procedures for homecare agencies under State programs serving consumers of all ages.

* Requires that states establish Consumer Boards to conduct oversight activities, provide input into the award and evaluation of the PRO and home help monitoring mechanisms, engage in consumer education, and receive input from homecare beneficiaries.

* Requires that PROs, state homecare monitoring mechanisms and ombudsman programs have toll-free hot-lines to receive questions and complaints from beneficiaries, providers and others concerning homecare quality issues.

* Requires that sanctions, including intermediate sanctions and civil penalties, be available to ensure compliance with quality assurance standards.

* Requires that DHHS set minimum proficiency standards for all persons delivering homecare services and fund training programs for personnel and caregivers. Encourages states to develop licensing requirements for home health providers.

* Requires that DHHS establish guidelines and provide funding for homecare training grants, for homecare demonstration projects, and for homecare quality assurance studies, including research on training and wage levels.

* Requires that DHHS implement and administer all provisions of the Act in conjunction with a National Homecare Quality Assurance Council of providers, consumers, states, accrediting bodies, fiscal intermediaries, PROs, researchers, and others.
HOME CARE PROBLEMS CONFRONTING THE ELDERLY

TESTIMONY SUBMITTED FOR THE RECORD

by the

AMERICAN ASSOCIATION OF RETIRED PERSONS

Senate Special Committee on Aging

April 27, 1987
Washington, D.C.
EXECUTIVE SUMMARY

The demand for home health care is growing rapidly for two reasons: the size of the frail, chronically ill, and disabled population is increasing and Medicare beneficiaries are leaving hospitals quicker and sicker under Medicare's prospective pricing system still needing transition care at home.

A. Medicare does cover post-acute care, but beneficiaries are experiencing significant problems in satisfying stringent eligibility criteria. And, the scope of covered benefits is being reduced through regulatory initiatives intended to curtail growth in the use of the home health benefit under Medicare.

B. The need for home health care by older, chronically ill Americans and their families poses the greatest threat of catastrophic costs. To obtain long term care services for chronic conditions, older Americans must spend down in order to satisfy Medicaid eligibility rules. And, Medicaid reimbursement favors institutional, rather than home care. Insurance against the high out of pocket costs for long term care is generally unavailable.

C. Besides high costs, consumers face the lack of uniform and effective regulation of the quality of care offered by home care agencies. Consumer protections are generally weak or nonexistent.

The American Association of Retired Persons recommends the following responses to these problems:

1. Existing regulatory efforts by HCFA and its intermediaries to arbitrarily and capriciously deny Medicare beneficiaries access to home health benefits must be stopped. Eligibility standards and scope of services should be broadened and clarified to meet the growing needs of beneficiaries for post-acute care. Patient eligibility for post acute care services should be determined prior to hospital discharge and should be binding on Medicare's fiscal intermediaries.
2. Chronically ill, disabled, frail and mentally ill persons need access to a broad range of coordinated and affordable long term care services. A prospectively paid case managed system could provide these essential linkages between medical and social services in a variety of settings.

3. American families need protection from the catastrophic costs associated with long term home health care services. Some combination of private and public long term care insurance must be developed to end the forced pauperization of American families needing chronic care services.

In sum, Medicare beneficiaries need protection against premature hospital discharge into a no-care or inadequate care zone. They need improved access to home based care for post-acute and chronic conditions. They need insurance protection against the financial cost of long term care. And, they need protection against substandard home health care.

To that end, AARP endorses S.1076 'The Medicare Home Health Services Improvement Act of 1987' and recommends its prompt adoption.

The American Association of Retired Persons (AARP) welcomes the opportunity to submit for the record testimony on home care for the elderly. With its 25 million members, AARP can speak confidently about the growing and unmet need for high quality home care for the acutely ill and frail elderly with multiple chronic conditions.

Improved access to comprehensive home health services is desperately needed for both post acute care by persons recently discharged from hospital and by those suffering from chronic illness and disability.

Those who need post-hospital transition care are being denied access to their Medicare benefits through a series of regulatory actions by HCFA and its fiscal intermediaries. This constitutes regulatory denial of a statutory benefit.

Chronically ill and disabled people and their families face catastrophic costs for long term care at home and in
institutions. The price of care is pauperization. The answer for them is improved coordination of a range of services and the financial protection afforded by long term care insurance.

Any home health care policy must address the pressing needs of both the acutely ill and the frail and disabled.

Need for Home Health

Because Medicare expenditures for home health care comprise less than 3% of total outlays, until recently little Congressional attention has been focused on this vital Medicare benefit. In fact, demographic trends and changes in Medicare Part A reimbursement methods have combined to make home health services increasingly important to people age sixty-five and older.

Specifically, the size of the frail, chronically ill, and disabled population is rapidly growing. According to the 1982 National Long Term Care Survey, 19% of those sixty-five and older have some degree of disability, while 4% of non-institutionalized older persons are severely disabled. Disability rates increase markedly with age, so that those who are age 85 and older are four times more likely to be disabled than younger Medicare enrollees. And, this age group is the fastest growing segment of our population. Consequently, the societal need for assistance in activities of daily living by disabled persons will increase rapidly.

As a result of this fact, the demand for home health services is growing rapidly today and will continue to grow in coming years. According to Bishop and Stassen's study in the Pride Institute Journal of Winter, 1986, growth in the number of persons served is the largest contributor to home health care expenditures. The rate of utilization tripled between 1974 and 1982.

Another contributing factor in the growing need for home health services is the pressure for early hospital discharge under the prospective payment system (PPS) inaugurated in 1983.

Van Gelder and Rernstein report in the same Pride Institute Journal that in fiscal year 1984, discharges from PPS hospitals to home health care were 1 1/2 times higher than the rate of discharge to home care from non-PPS hospitals. The authors
report that all of the studies by the U.S. Department of Health and Human Services find that the rate of discharge to home care rose sharply after PPS was implemented; that older patients are being discharged earlier and sicker; and that home health care providers are giving more skilled and intensive care to clients now than they were before PPS began.

These formal findings are corroborated by informal surveys of providers, by testimony submitted to Congress, and by letters we have received from distraught and angry members who need and cannot obtain home care. Our members write heart-wrenching letters about being forcibly discharged from hospitals while still needing extensive care. Unmarried older persons are being sent home from hospitals despite the fact that they are too ill to care for themselves. Many of our letters are from the spouses and children of recently hospitalized people whose need for physical and medical care exceeds the time, strength, and skill of family members into whose care they are discharged. In sum, the demand for home health care services is being stimulated by the growing numbers of acutely ill people who are being denied post-acute transition care in hospitals.

Inadequate Benefits

While the need for home health care is growing for both chronically and acutely ill persons, the Medicare home health benefit is both inadequate and often unavailable.

Current problems in the scope and structure of Medicare's home health benefit can be attributed to several causes: determination of eligibility, scope and duration of services, and lack of protection for consumers.

Eligibility: Although the requirement of prior hospitalization was eliminated in 1981, eligibility for home health benefits under Medicare is still linked to acute, temporary illness rather than the need for chronic care. To be eligible for this Medicare benefit, individuals must be certified by a physician to need part-time or intermittent skilled nursing care.

In an effort to curtail use of this benefit, HCFA has been formally and informally adopting increasingly stringent
definitions of "part-time" and "intermittent" care. Additionally, the definition of being "home bound" - another eligibility criterion - has also been subject to varying and arbitrary interpretations.

For example, in 1975, HCFA's Health Insurance Manual-13, section 3119.6 defined intermittent or part-time care to average 20 hours or less a week for up to 100 hours a month. By 1981, HCFA's Home Health Agency Manual Transmittal No. 127 limited care to 1-2 hours a day, 2-3 times a week. Providers had to justify any additional levels of care. For the very ill, HCFA permitted "medically reasonable and necessary" aide services on a daily basis for no more than 2-3 weeks. A year later, HCFA's Transmittal No. 137 provided a guideline of nine hours a week.

Several problems have been identified by providers and beneficiaries. Fiscal intermediaries vary in their interpretation of "part-time" care and retroactive denials of coverage are not uncommon. In some states, receipt of 1-5 care days a week is considered to be daily care and thus ineligible. In other states, clients may not receive more than one visit a day, even if the purpose of the visits differs.

Variations in the interpretation of "home bound" have also resulted in denials of eligibility to those in need of care. Under current guidance (Health Insurance Manual-11, Section 208.4), a person must be normally unable to leave home except for infrequent periods of relatively short duration. The imprecision of these words has led to absurd situations where people have been denied coverage because they left home to receive chemotherapy.

The GAO has repeatedly criticized the homebound requirement as unduly restrictive, yet it is retained. Consequently, ambulatory people who can't dress, bathe or prepare meals can be denied care. Additionally, improvement in mobility - a goal of home health services - could jeopardize receipt of needed home services.
Finally, if all one needs initially is occupational therapy, eligibility will be denied. Yet, one can continue to receive such therapy after skilled nursing care is no longer needed.

Because of these and other arbitrary and capricious interpretations of eligibility criteria, untold millions of older Americans may be denied access to necessary care. HCFA data show that rates of denial for home health care claims are increasing. Between FY 1979 and 1983, denials of Part A home health bills rose from 2.8% to 3.7%. Between FY 1982 and 1983, the number of these denial notices sent to beneficiaries increased 8.9%. By fiscal year 1987, 6% of all such claims were denied.

Yet, this may only be the tip of the iceberg of unmet or denied care. Since providers are now liable for the cost of care provided to persons later determined to be ineligible, home care agencies may be refusing service to doubtful cases. We have no data on the extent of unmet need for post acute care service, but present conditions lead one to assume that the problem is serious.

Furthermore, we don't know the extent to which beneficiaries and their families are directly paying for needed services to supplement the benefits provided under Medicare. There is anecdotal evidence that when families do supplement the home care benefit, they may thereby lose eligibility for services. In Connecticut, for example, the LAMP program (Legal Assistance to Medicare Patients) reports that if family members provide care to people receiving home health services, the client may be found to need more than "part-time" or "intermittent" care and then be denied all home health care services.

Another weakness of current eligibility standards is that the social circumstances of patients are not considered. It is now commonplace for weak, ill people to be sent home from hospitals when there is no family member to care for them. Unless they need skilled nursing care, they cannot receive home health services despite their obvious inability to care for themselves.
Scope of Services

As we noted, the Medicare home care benefit offers both too little volume of care for many people and is unduly geared to meet an acute medical need. The growing cohort of frail and mentally disabled people with long term needs for care -- both skilled and personal -- is not being addressed by Medicare. We lack a long term care system encompassing medical, social, and personal care services provided in a variety of community, home-based, and institutional settings. For example, Medicare does nothing for the Alzheimer's patient whose family is struggling valiantly to avoid institutionalization.

The primary source today of home-based long term services for the elderly is family members. These free services are supplemented by the Older Americans Act and Medicaid. Yet, Medicaid eligibility standards vary enormously, as does the range of provided services. Only eight states offer personal care services to the categorically needy; sixteen states offer this service to both the medically and categorically needy. Only two states offer unlimited service. The fourteen states which require prior authorization for part-time nursing care account for 83% of Medicaid expenditures for that service. The thirteen states requiring prior authorization for aide services account for 83% of these expenditures. Five states do not provide homemaker services.

This patchwork of rules and coverage is confusing and inconsistent. And, it is too soon to tell whether HCPA's recent consolidation of intermediaries responsible for home care bills will produce more uniform application of the rules.

The unavailability of requisite home-based services forces untold numbers of older Americans to jeopardize their health; pay out-of-pocket for needed but uncovered services; and finally to enter an institution.

Chronically ill, frail, and/or disabled people cannot obtain home health benefits under Medicare. To obtain these services under Medicaid, older Americans must spend down in order to meet
eligibility criteria. We know the financial catastrophe faced by those who enter nursing homes. Most private paying residents are pauperized within a short time from entry. A Congressional study found that nearly half of unmarried residents age 75 and over are pauperized within thirteen weeks of entry. Three-fourths of these residents are impoverished within a year. Older Americans desperately need financial protection against the catastrophic costs of long term care. Yet, long term care insurance is not readily available from private insurers and public policy has failed to remedy this problem.

Some estimate that as many as 20% of nursing home residents could live at home with community-based services. When needed services are unavailable, frail elderly persons are forced into institutions where they face immediate and crushing costs. At present, about half of all nursing home costs are paid directly by consumers.

Provider Qualifications

Another problem in the area of home health is the absence of quality standards for providers. This essential service sector is largely unregulated and opportunities for abuse and substandard care abound. Consumers who do obtain home health services are generally at the mercy of strangers who may be untrained for their duties, unsupervised, incompetent and/or dishonest. The home care field is growing and changing rapidly; between 1981 and 1985, there was a 74% increase in the number of Medicare certified home health agencies. The greatest growth has been among proprietary agencies, largely in response to the 1980 Omnibus Reconciliation Act which permitted Medicare certification of proprietary agencies in states without licensing laws.

Licensing and certification standards vary greatly among our states. While HCFA is primarily concerned about reimbursements, hardly anyone is formally charged with assuring access to and quality of care. There are few avenues of recourse open to persons inappropriately denied care or given substandard care.
Indeed, in some instances there may not be a standard of care. Caveat Emptor is an irresponsible guide to our most vulnerable citizens. Consumer protection must be built into our home health care programs.

**NEEDED SOLUTIONS:**

AARP believes this situation represents a failure of public policy. A crisis in care confronts Americans today -- a crisis with serious health, social, and financial costs. American families desperately need accessible, high quality, comprehensive, coordinated post acute and long term care home health benefits. Ultimately, home health services should combine the following features:

- it should cover both acute and chronic conditions;

- provide a full array of well trained and supervised skilled, personal, and homemaker services in the home as well as in an institution;

- when appropriate be linked to a hospital discharge planning process;

- encourage participation by family members, friends, and community volunteers;

- cap out of pocket expenditures so that people are not pauperized by their need for long-term care;

- be based on the insurance principle of shared risk and predictable individual costs;

- provide for data collection and evaluation to measure both access to care and quality of services delivered;

- meet reasonable and uniform quality standards; and

- include consumer protection and participation.
To achieve these goals, we support prompt enactment of S.1076, the Medicare Home Health Services Improvement Act of 1987. The bill will ensure improved access to home health benefits under Medicare Part A. The bill clarifies the definitions of "intermittent" and "homebound"; expands the frequency and duration of daily visits that are initially authorized; mandates minimum training and certification of home health caregivers; requires HCFA to publish for comment all guidelines and interpretive rules; mandates frequent unannounced provider surveys including outcome oriented patient evaluation; authorizes HCFA to impose fines and civil penalties for noncompliance with required standards and timetables for corrective action; and requires HCFA to publish provider directories listing the current compliance status of Medicare-certified providers. These provisions could measurably improve consumer protections and the quality of care provided.

In addition, affordable and adequate long term care insurance must become more readily available. AARP is open to the notion of an increased Medicare premium in exchange for true stop loss protection against the costs of long term care. We are also exploring the possibility of private sector long term care insurance.

We further recommend prospective payment for a case managed system of long term care. Community based care will require a continuing combination of public and private sector funding. AARP supports the Medicaid 2176 Waiver program and deplores restrictive regulations which serve to hamper its operation. We recognize that we have a long way to go before existing services meet these criteria. The task is large; the need is great. We cannot afford to wait in developing the solutions.

AARP welcomes the opportunity to work with this Committee toward solving these problems in home care.
May 13, 1987

Honorable John Melcher
Chairman, Senate Special Committee on Aging
Washington, D.C.

Dear Senator Melcher:

The ABA Commission on Legal Problems of the Elderly was pleased to hear that you were conducting a hearing on the issue of home care quality. As an interdisciplinary body constituted to analyze and respond to the law-related needs of the elderly, we believe that the issue is of considerable importance. I have enclosed a statement based on our Commission's own report on the state of the art of home care quality assurance, entitled "The Black Box of Home Care Quality."

Thank you for the opportunity to discuss this important issue. I hope you continue your efforts in this area.

Sincerely,

John H. Pickering
Chairman

Enclosure
STATEMENT OF
JOHN H. PICKERING
ON BEHALF OF
THE
AMERICAN BAR ASSOCIATION
COMMISSION ON LEGAL PROBLEMS OF THE ELDERLY

The Commission on Legal Problems of the Elderly of the American Bar Association appreciates the opportunity to address the important issue of "The Role of the Older Americans Act in Assuring Access to Quality Home Care." The Commission, established in 1978 by the ABA Board of Governors to address the law-related needs of the elderly, is an interdisciplinary group that includes practicing attorneys, legal educators, gerontologists, elderly law specialists, government officials and senior citizen advocates.

The testimony which we are presenting is the view of the Commission's and has not been approved by the ABA Board of Governors or House of Delegates.

As chairman of the Commission, I have had the privilege and challenge of overseeing our Commission's efforts in examining the status of home care quality assurance mechanisms at both the federal and state level. These efforts led to the publication of a report entitled "The Black Box of Home Care Quality," released in August 1986 in conjunction with a hearing on the topic convened by Representative Roybal, Chairman of the House Select Committee on Aging.

Since this Committee is already familiar with that report and its recommendations, I will not repeat its contents here. Instead, let me suggest
five fundamental questions, derived from the report, that ought to be asked in creating any proposed quality assurance system:

1. Is the system as comprehensive and uniform as possible in the scope of agencies covered, services covered, and data collected?

2. Does the system focus on the quality of care actually provided, or instead, only on the provider's capacity to render care?

3. Does the system effectively empower consumers by means such as:
   a. providing consumers with clear and consistent information about providers, services, costs, and consumer rights?
   b. involving consumers as a primary participant in evaluation and monitoring?
   c. providing consumers with simple and effective means of redress when problems or deficiencies in care arise?

4. Does the system ensure that care is provided by well-trained and supervised care givers?

5. Does the system ensure the effective monitoring of the services delivered to consumers and the use of a strong, but flexible, range of sanctions?

We believe these questions help elucidate the basic consumer-oriented assumptions that ought to be
fundamental to a quality assurance system. Yet, beyond those basic assumptions, there is a threshold regulatory question that has not been squarely faced by the witnesses before this Committee: what is the proper federal role in creating home care quality? The very title of this hearing begs that question in the context of the Older Americans Act.

The Federal government sets the basic mold for what happens in home care services at all levels -- federal, state local, public or private. One need only look at the Medicare program for an example. Since its inception, Medicare's home health care "conditions of participation" have been the benchmark for home care regulation, even though the scope of Medicare's home health benefit is really quite limited. Licensure laws and regulations -- the predominant form of state regulation over home care -- have largely mimicked the language of the conditions of participation, at least until recently.

The other major federal funding sources for home care--Medicaid, Social Services Block Grants and the Older Americans Act--acrose to serve discretely identified needs and target populations. Despite the best of intentions, the combination of these programs did not provide an integrated continuum of services, but rather a fragmented and incomplete care system with inadequate and uncoordinated quality assurance mechanisms.

For the last several years, many states have desperately tried to impose some order and coordination among these federal and various state-funded programs. To accomplish this, states have variously tried case management strategies, channeling initiatives, state supplements, cash-outs and other bridging mechanisms. Many of these initiatives have been supported by the federal government. Yet, the basic structure of federal funding still fosters fragmented care and, consequently, fragmented quality assurance.
This is not to suggest that all federal funding sources be combined into one mega-program. There are valid reasons for the distinct identities of these programs. At the same time, the goal of quality of care perhaps demands that these programs start talking the same language in terms of definitions, standards, enforcement, and data collection. This goal perhaps also demands that these programs throw out some of the entrenched medical model versus social services model conceptualizations and, instead, pay their fair share of a coordinated case assessment, case management, and quality assurance system.

This cannot happen unless the Federal government begins to break some of the legal/structural barriers among its own programs and set the basic parameters for such a system. Without the structural bridges, new quality assurance mechanisms may still emerge, but they may more closely resemble the many-headed Hydra of mythology than a system of accountability. For example, consider the need for the training and supervision of home health aides and other supportive personnel. We may all finally agree that minimum federal standards are needed; but, are we better off with common definitions and standards for training and supervision—or with differing standards depending upon whether these personnel are funded by Medicare, Medicaid, Social Service Block Grants or the Older Americans Act? This is one of many possible areas in which the Hydra can be slain.

Case management is another. While its value as a dollar saver is still debated, its value as a quality enhancer has gained widespread acceptance. Yet, under present structures, its growth could prove strangely ironic, for instead of a case manager, we may witness many case managers—the home care agency
social worker, the hospital discharge planner, the physician, the area agency on aging, the insurance company, the private case manager, and more.

Those illustrations only highlight the need for Congress to rethink the aims and approaches of the key authorizing acts. While this Committee is specifically examining the role of the Older Americans Act, its vision needs to be much greater than that Act itself. If the example is set, the states will need little prodding to follow suit.
The American Federation of Home Health Agencies appreciates the opportunity to address the vital issue of quality of care in home health services before the Senate Special Committee on Aging.

We wish to address this concern in two ways: first, within the context of the current administration of the Medicare home health benefit and the implications therein for quality of care, and second, by recommendations to address specific concerns that may arise regarding provision of quality care in the home.

To begin with the current climate of the Medicare home health benefit, we look forward to the day when home health personnel can concentrate their energies on provision of the highest quality home health services instead of on shuffling a load of unnecessary paperwork and playing a guessing game with the Health Care Financing Administration and its fiscal intermediaries as to whether services will be covered, even though a patient clearly appears to meet every coverage criteria.

Home health agencies are already reeling under the impact of massive denials from intermediaries, which in turn are under pressure from HFEA to produce at least five dollars in denials for every one dollar they receive for medical review and utilization review. We have seen a significant increase in denials over the last year to eighteen months. And if HFEA persists in its claim that one third of home health services now being provided should in fact be denied, the current disruption would pale in comparison to the upheaval that would result. Quality of care along with access of beneficiaries to services would be the victims once again.

Denial of services, in whole or part, to the very sickest and most debilitated patients is now common. We shudder to think what the outcome will be if the level of denials ever reaches thirty-three percent.
One type of service with particular bearing on quality of care is that of medical social worker. Social workers are trained to deal with the psychological and social dimensions of a patient's situation, to make overall assessments of the efficacy of care being provided, and to alert an agency to any problems that develop. Without dealing with the psycho-social aspects of care of elderly and disabled beneficiaries, many of whom are confused and alone, a home health agency cannot provide the services that a patient's situation requires.

Unfortunately, medical social services are scarcely available under current dictates of HCFA and its intermediaries, which rarely allow more than one or two such visits to a patient. In addition, application of cost limits by discipline rather than in the aggregate makes it difficult, if not impossible, for many home health agencies to provide medical social services. There is no profit in the Medicare home health benefit and no way to offset losses in high-cost low-utilizing disciplines; without the ability to offset over-limit disciplines with those under the limits, HMOs are discontinuing provision of medical social services and other rehabilitative services such as physical therapy and speech therapy.

Another problem within the current system with implications for quality of care is the imposition of onerous regulatory and paperwork burdens that cause agencies to divert their resources away from the provision of patient care. Not a dime's worth of the added expense associated with these burdens goes to beneficiary services or measurement of quality of care. The intent is pure and simple restriction of reimbursement.

A case in point is HCFA's "minimum" data element series, Forms 485-488. These forms are proving to be enormously costly in terms of time and diversion of the energies of highly skilled personnel. Nurses would rather concentrate on patient care for which they have been trained, but many have been reduced to paper pushers in an attempt to forestall devastating denials emanating from forms which give them so many opportunities to trip up. We recommend withdrawal of the 485 series.

Massive denial of services is HCFA's preferred method of curbing utilization and the growth of the home health benefit. Increased utilization and outlays for home health are inevitable with the implementation of prospective payment for hospitals and the aging of the population. There is an element of preventable growth, however, that has not been addressed. The proliferation of home health agencies in states without certificate of need requirements is a prime factor in increased outlays under the benefit. A greater number of agencies per se does not lead to a reduction in the cost of services through competition. In fact the opposite is true. Where HMOs are allowed to proliferate without control, the result is an increased number of agencies seeking to serve a finite number
of patients. New agencies will have higher than average costs in the startup years, while reduced utilization will drive up the per visit costs of established agencies, whose set administrative and overhead costs are then spread over fewer patients. More funds thus serve the same basic patient populations. We urge a national certificate of need requirement or a moratorium on the issuance of provider numbers to HHAAs to decrease the costs of providing services and redirect Medicare funds towards patient care and away from administrative costs. This in turn would serve to control outlays and reduce the pressure to deny needed services to beneficiaries. Possession of a provider number should be tied in closely with quality assurance; an agency which does not satisfy quality standards would forfeit its participation in the Medicare program. States are in a better position to assess quality with a stable number of home health agencies than they are where absence of certificate of need has led to geometric increases in the number of HHAAs in a short period of time.

We wish to emphasize here that factors driving home health agencies to reach or exceed their cost limits—massive denials, implementation of numerous requirements such as Forms 485-488, proliferation of agencies—are forcing administrators to take measures to avert debilitating losses. In a system as labor-intensive as home health care, this means that many agencies must employ less-experienced, less-skilled personnel with lower salary demands, and must discontinue over-cap rehabilitative services. Policies which have such implications for quality and access to care are short-sighted financially and completely fail to take into consideration the welfare of beneficiaries for whom the Medicare program exists.

Quality is a difficult concept to define and assess; and it is much more difficult to measure in the home than in an institution. We do not believe it is very practical to send independent assessors into patients' homes to judge the quality of care received by elderly and debilitated beneficiaries. Such beneficiaries are not very reliable sources for evaluating services they may have received a number of weeks in the past. This type of monitoring system would also be costly. (Visits to patients now mandated by NCPA unfortunately are not geared toward quality assessment; they are but another tool to ferret out denials.) Quality ultimately has to come from home health agencies themselves and from beneficiaries and their family members as consumers of home health services.

We believe it would be more effective to implement mechanisms such as the following, some of which require changes in Federal law, NCPA regulations, or inducements to state action:

- Every beneficiary and/or responsible family member should be provided with a patient bill of rights upon admission to the services of a home health
agency. This document should include a description of the HFA's grievance mechanism and the name and number of the agency's patient advocate (and the name of the state review board noted in the following suggestion).

Any complaints regarding care should be taken straight to the agency's administrator by the designated advocate. Since many beneficiaries and their families find themselves baffled by the Medicare bureaucracy and by denial of services, basic information on eligibility, benefits, and payments should also be provided at admission. (We are submitting with our testimony a sample of a patient bill of rights, this one required to be provided to all beneficiaries by Florida home health agencies.)

- An independent review board should be set up in each state, consisting of consumers, beneficiaries and their families, HFA administrators, physicians, and other appropriate representatives, to which patients and their advocates can bring complaints pertaining to care given or possible abuse. Such a board should be given authority to investigate allegations of inferior care and abuse and to take appropriate action.

- Tied in with the previous suggestion, the review board or another entity in each state should keep records on HFA personnel fired for provision of inferior care or abuse of patients, and periodically send alerts to all HFAs operating in the state, listing names compiled and reasons for dismissal. (We realize that there are legal implications which would have to be examined pertaining to the dissemination of such information.)

- To minimize the chance of abuse and to insure accountability, states should be given incentives to license all agencies, registries, and individuals who provide health-related care or homemaker services in beneficiaries' homes. Training requirements should be developed for all non-professional caregivers. (One model for such a requirement went into effect in Florida this past July 1. A copy is provided with this testimony.)

- Licensing and training are especially urgent as denial of services under the Medicare benefit is causing families to turn to other sources, of unknown reliability and professionalism, to provide services to patients in desperate need of care.

- All home health caregivers, including employees of Medicare certified agencies, should be required to receive a specified number of hours of continuing education per year in their field.

- A basic patient right—freedom of choice in selection of the caregivers—is increasingly being violated with impunity by the closed referral systems which are proliferating around the nation. HFA should require that the referring entity, including physician and hospital, divulge in writing any financial interest or corporate relationship, no matter how small, in an agency to which it directs a patient. At the same time, in
communities with more than a sole home health agency, every beneficiary referred for home health services through a discharge planner or social worker should be provided with the name of at least two agencies from which they might receive care. Real and beneficial competition will flow from the provision of a choice to patients. Finally, beneficiaries should be told of their absolute right to receive services from the agency of their choice. We have heard of patients who feel threatened with loss of health services when they request an agency not of the referring entity's choosing.

On a cautionary note, we do not know how badly quality assurance systems are broken or even whether they are. We believe that we must first assess this question, and then proceed to devise the most effective solutions to any problems identified.

The recent report on home health aide services by Richard Russerow, Inspector General of the Department of Health and Human Services, has raised a number of concerns. We caution that this report could distort discussion of the quality of services provided by both home health aides and skilled personnel under Medicare. The number of beneficiaries the Inspector General included in his sample is quite limited. He reviewed only sixteen home health agencies in six states and 66 patients, while nationwide there are approximately 5800 Medicare certified home health agencies serving over 1.5 million beneficiaries each year. But rather than get sidetracked over methodology and the size of the sample, we urge that the Aging Committee look towards specific recommendations addressing quality concerns, such as those we suggest above, and continue to urge HCFA to issue at last the training standards for home health aides mandated by Congress.

We look forward to working together with the Senate Special Committee on Aging to ensure that our nation's elderly and disabled citizens have access to essential home health services of the highest quality possible.

Respectfully submitted,

Margie B. Mills
President
The patients and/or responsible parties have the right to expect . . .

The highest quality of care in their place of residence.

A home health agency of their choice, including full knowledge of all services provided, alternatives available, or the option to refuse care.

That the chosen lifestyle, spiritual and emotional being will be treated with the utmost dignity and respect by all agency representatives.

That the home health agency complies with all applicable state and federal rules and regulations.

Continuation of the care initiated in the physician's office, clinic, hospital or nursing home.

That the care will be provided by experienced and qualified personnel under the direction of the patient's physician.

The entire health team including the patient will develop an individualized plan of care.

Education regarding their disease, health needs, safety and emergency measures.

Confidentiality of and access to medical records according to the Florida Statutes.

Rehabilitation to the maximum level of independence.

That acceptance of health responsibilities will be promoted and encouraged by all health team members.

An explanation, upon request, of the charge for home health care.

Co-operation of the patient and/or family is necessary in order to achieve the goals of this Bill of Rights.

This Bill of Rights is an ethical declaration for patients accepted for care in conformance with published policies of the home health agency and does not imply or constitute obligation for payment of services by the insurance carrier.

The Quality Assurance Committee wrote and presented this Bill of Rights for Home Health patients to the membership for ratification in October 1979.
HOME HEALTH SERVICES ACT
AND
MINIMUM STANDARDS FOR
HOME HEALTH AGENCIES

HOME HEALTH AGENCIES

400.481 Short title, purpose.
400.482 Definitions.
400.483 Agencies to be licensed.
400.484 License required; fees, display.
400.485 Application for license.
400.486 Denial, suspension, revocation of license, grounds.
400.487 Expiration of license; renewal; conditional limits or permit.
400.488 Suspension or revocation of license; grounds.
400.489 Inspection proceedings authorized.
400.490 Right of inspection.
400.491 Establishment and review of plan of treatment.
400.492 Clinical records.
400.493 Information confidential.
400.494 Plans establishing minimum standards.
400.501 Prohibited acts, penalties for violation.
400.504 Agencies to be given reasonable time to comply with rules and standards.
400.505 Licenses of additional home health agencies.

400.481 Short title, purpose.—
(1) The act shall be known and may be cited as the "Home Health Services Act.".
(2) The purpose of this act is to provide for the licensing of home health agencies which are certified or seek certification as a Medicare home health service provider and to provide for the development, establishment, and enforcement of basic standards which ensure the safe and adequate care of persons receiving Medicare home health services in their own homes.

400.482 Definitions.—When used in this part, unless the context otherwise requires, the term:

(a) "Department" means the Department of Health and Rehabilitation Services.

(b) "Home health agency", hereafter referred to as "agency", means any public agency or private organization, or a subdivision of such an agency or organization, whether operated for profit or not, which provides home health services and which is certified or seeks certification as a Medicare home health service provider, except as provided in 400.505.

(c) "Home health services", hereafter referred to as "services", means health and medical services and medical supplies furnished to an individual by a home health agency or by others under arrangements with the agency, on a visiting basis, in a place of residence used as an individual's home. Such services may include, but are not limited to, the following:

(a) Personal or intermittent nursing care.
(b) Physical, occupational, or speech therapy.
(c) Medical social services.

(d) Home health aide services, home health aide services, and nutritional guidance.
(e) Medical supplies, other than drugs and biologicals prescribed by a physician and the use of medical appliances.

(f) Services rendered to individuals who are 65 years of age or older and are residents of a nursing facility or of a home health agency.

400.486 Agencies to be licensed.—Any agency providing home health services as defined in this act shall be licensed by the department to operate in this state. However, any agency or organization operating by an agency of the federal government shall be exempt from the provisions of this act.

400.487 License required; fees, display.—
(1) It is unlawful to operate an agency without first obtaining from the department a license authorizing such operation.

(2) The annual license fee required of an agency shall be in an amount determined by the department to be sufficient to cover the costs incurred in carrying out its responsibilities under this part but not to exceed $300. However, counties or municipalities applying for licenses under this part can be exempt from the payment of license fees.

(3) The license shall be displayed in a conspicuous place in the agency and shall be valid only in the possession of the individual, firm, partnership, association, or corporation to which it is issued and shall not be subject to sale, assignment, or other transfer, voluntary or involuntary, nor shall a license be used for any agency other than that for which it originally issued.

400.505 Licenses of additional home health agencies.

400.507 Application for license.—
(1) Application for license shall be made to the department on forms furnished by it and shall be accompanied by the appropriate license fee.

(2) The applicants shall file with the application satisfactory proof that the agency is in compliance with the act and any rules and minimum standards promulgated hereunder, and proof of financial responsibility to the department to conduct the agency in accordance with the requirements of this act.

(3) The department shall not issue a license to a home health agency which fails to receive a certificate of need under the provisions of s. 381.453, Florida Statutes.
460.476 Establishment and review of plan of treatment—
(1) A plan of treatment shall be prepared for each
patient receiving care or treatment provided by a
licensed home by or for a physical, occupational, or
speech therapist, by or for the physician who is
responsible for the care of the patient. The original
plan of treatment shall be signed by the therapist and
reviewed by the physician in consultation with
agency personnel involved in providing care to the
patient. Such plan shall include all information as to
the severity of the patient's disease or illness, in
such detail as to assure to the patient the best care
available according to the standards of the medical
profession as set forth in the standards of the
American Medical Association and as adopted by the
agency. Such plan shall be reviewed and signed by
the physician at least every 30 days, or more often
if necessary. The plan must be provided as
prescribed by the Board of Health.

460.477 Expansion of license renewal; conditional license or permit—
(1) Licenses issued for the operation of an agency,
unless sooner suspended or revoked, shall expire 1
year after the date of issuance. Licenses shall be
renewed if the applicant has met the requirements
established under this act and has not violated
hereunder. The agency shall provide the
applicant with the application satisfactory proof that
the 
(2) Any agency having a license on October 1, 1983
shall be deemed to meet all standards on the date of
issuance of the license, except as to those
requirements of the effective date of this act, which
shall become effective on or after the date of the
issuing agency.

460.478 Disposition of fees collected.—All fees
collected under this chapter shall be deposited in the
proper fund by the department for the administration
of the act.

460.479 Injunction proceedings authorized.—The
department may institute injunction proceedings in a
court of competent jurisdiction whenever any
practice or act of any licensed agency or
personalties promulgated hereunder constitutes an
emergency aff

460.484 Right of inspection.—Any duly authorized
officer or employee of the department shall have
the right to make such inspections and investigations
as are necessary in order to determine the state of compliance
with the provisions of this act and the rules or standards
in force. Any such inspection shall also extend to
any agency which the department has reason to
believe is being operated as an agency without
a license, but no such inspection of any agency shall
be made without the permission of the owner or
person in charge thereof, and a warrant as to its
obtained from a court of competent jurisdiction. Any
inspection made by an agency license or renewal thereof made pursuant to
the act shall constitute permission for any inspection of the
agency for which the license is issued, in order to facili

tate the review of the information submitted in or in
connection with the issuance of the same.

460.485 Establisheent and review of plan of treat
ment—
(1) A plan of treatment shall be prepared for each
patient receiving care or treatment provided by a
licensed home by or for a physical, occupational, or
speech therapist, by or for the physician who is
responsible for the care of the patient. The original
plan of treatment shall be signed by the therapist and
reviewed by the physician in consultation with
agency personnel involved in providing care to the
patient. Such plan shall include all information as to
the severity of the patient's disease or illness, in
such detail as to assure to the patient the best care
available according to the standards of the medical
profession as set forth in the standards of the
American Medical Association and as adopted by the
agency. Such plan shall be reviewed and signed by
the physician at least every 30 days, or more often
if necessary. The plan must be provided as
prescribed by the Board of Health.

460.486 Clinical records.—The home health agency
shall maintain for each patient a clinical record which
includes the services the agency provides directly
and those provided through the agency by
another agency. Such records shall contain personal data and
other pertinent information, the plan of treatment, or other such
information as is necessary for the safe and adequate care of the
patient. When such services are terminated, the
record shall show the data and reason for
termination.

460.487 Information confidentiality.—Information
received by or on behalf of the home health agency
through reports or inspection shall be deemed
privileged and confidential information and shall not be
disclosed to any person other than the patient without
the written consent of the patient or his
guardian.

460.551 Probable cause to believe violation—
(1) It shall be unlawful for any patient or public body to
take or sell to any person by any means whatsoever, home health services as defined in this act
without obtaining a valid current license. It is unlawful for
any person to sell to any patient or public body the services of
such a service or to sell or hold out to the public that it
provides a service that it does not actually provide.

(2) Any person found guilty of violating subsection
(1) shall be guilty of a misdemeanor of the second degree,
ground punishable as provided in a 775.063. Each day of
continuing violation shall be considered a separate
offense.

460.504 Agencies to be given reasonable time to
by or by any other person or by any person
or by any other person or by any person
or by any person

460.505 Licensure of additional home health agen
cies—
(1) The purpose of this section is to provide for the
licensure of every home health agency and to
safeguards against regulation as a Medicare home health agency
and to provide for the development of standards and
enforcement of public interests

(2) Any home health agency not hereinafter
subject to licensure under this act shall be, effective July 1, 1985,
subject to all regulatory and other requirements of the
460.481-460.504, except for the requirement of
obtaining a certificate of need as provided under chapter
381. Agencies licensed under this section shall
be subject to Medicare certification.

(3) Any home health agency in operation as of July 1, 1985,
shall be given a reasonable time by the
department, not to exceed 1 year from July 1, 1985,
with which to comply with department rules and obtain
licensure.
10D-68.001 Purpose.
10D-68.002 Definitions.
10D-68.003 License Required.
10D-68.004 Licensure Procedure.
10D-68.05 Prohibited Acts. (Repealed)
10D-68.06 Right of Inspection. (Repealed)
10D-68.07 Existing Home Health Agencies. (Repealed)
10D-68.008 Scope of Services.
10D-68.009 Personnel Policies.
10D-68.010 Administration.
10D-68.011 Nursing Director
10D-68.012 Registered Nurse.
10D-68.013 Licensed Practical Nurse.
10D-68.014 Home Health Aide.
10D-68.015 Physical Therapist and Physical Therapist Assistant
10D-68.016 Speech Pathologist.
10D-68.017 Occupational Therapist and Occupational Therapy Assistant.
10D-68.018 Social Worker.
10D-68.019 Homemaker.
10D-68.020 Acceptance of Patients.
10D-68.021 Patient Care Plan.
10D-68.022 Client Service.
10D-68.023 Utilization Review. (Repealed)
10D-68.024 Administration of Drugs and Biologicals.
10D-68.025 Companion Sitter.
10D-68.026 Penalties.
RULES OF THE
STATE OF FLORIDA
DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES
HEALTH PROGRAM OFFICE
CHAPTER 100-68, FLORIDA ADMINISTRATIVE CODE
MINIMUM STANDARDS FOR HOME HEALTH AGENCIES
AMENDING SECTIONS 100-68.001 THROUGH 100-68.022

10D-68.002 Definitions. The following terms in the
context of this law shall mean:

(1) Approved school - a school of nursing or a school for
the education of practical nurses approved by the Florida State
Board of Nursing; a school of physical therapy approved by the
American Physical Therapy Association; or the Committee on Medical
Education of the American Medical Association; or the Committee on
Medical Education of the American Medical Association in
collaboration with the American Physical Therapy Association; a
graduate school of social work accredited by the Council on
Social Work Education; a school offering an occupational therapy
curriculum accredited jointly by the Council on Medical Education
of the American Medical Association and the American Occupational
Therapy Association.

(2) Branch office - a location or site from which a home
health agency provides services within the county of the parent
agency which shares administration and supervision and other
services. The branch office is included in the parent agency
license.
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42) Client’s record - an accurate chronological account of services provided to a person, as well as other permanent information necessary to provide care, dated and signed by the agency staff providing care.

(3) Companion or Sitter - a person who provides designated support services in the home under agency supervision.

(4) Department - the Department of Health and Rehabilitative Services.

(5) Home Health Aide - a non-professional person who provides personal health care services for a patient person in the home, under the supervision of a licensed health care professional who is an employee of or contractor with the agency.

(6) Home Health Agency - hereinafter referred to as "agency," means any person not licensed by the Department or the Department of Professional Regulation, public agency or private organization, or a subdivision of such an agency or organization, whether operated for profit or not, which provides home health services as defined in sections 400.462(1) and 400.505, F.S., including any agency to which fees are paid for the rendering of home health services including agencies known as registries, agents and brokers provided such fees are not one-time, intermittent or irregular placement fees which amount to 50 percent or less of the costs of services actually provided on the first day of placement.

(7) Home Health Services - hereinafter referred to as "services," means health and medical services and medical supplies furnished to an individual by a home health agency or by others under arrangements with the agency, on a visiting basis, in a place of residence used as an individual's home. Such services shall include one or more of but are not limited to the following:

(a) Part-time or intermittent nursing care;
(b) Physical, occupational, or speech therapy;
(c) Medical social services; homemaker services, home health aide services, and nutritional guidance; and
(d) Medical supplies, other than drugs and biologicals prescribed by a physician, and the use of medical appliances.

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(a) Any other health-related services necessary to maintain
the patient in the home.

(2) Homemaker - a non-professional person who provides home
management services for a patient and family, performs household
chores under agency supervision.

(3) Licensed practical nurse - a person who is currently
licensed to practice nursing under the direction of a physician
or registered nurse pursuant to Chapter 464 of the Florida
Statutes.

(10) Medical Social Worker - a professional person who
has a degree in social work and who counsels patients and
families so that they may adjust to social and emotional factors
related to the patient's health problems.

(11) Occupational Therapist - a professional person who
is licensed to practice occupational therapy pursuant to Section
468, Part V, F.S., evaluates and treats individuals whose ability
to cope with the effects of illness, disabilities, or disease, are
impaired or threatened by development and factors that affect
processes, physical injury or illness, or psychological and social
disability.

(12) Occupational Therapy Assistant - a person licensed
to assist in the practice of occupational therapy pursuant to the
provisions in Chapter 468, Part V, F.S.

(13) Part-time or intermittent nursing care - any nursing
care provided on a visitation basis for a period of less than 24
hours.

(14) Patient Care Plan - a coordinated and combined
care plan prepared by the nurse case manager and in
collaboration with each discipline providing service for the
patient and family.

(15) Physical Therapist - a professional person who is
licensed to practice physical therapy pursuant to Chapter 486,
F.S., treats any disability, injury, disease, or other condition of
health by the use of physical agents and other properties of
the body, heat, electricity, exercise, massage, radiant energy;
ultrasound, water, or equipment.
(16) (b) Physical Therapist Assistant - a person who is licensed to practice physical therapy procedures as defined in Chapter 486, R.S., the physical therapy procedures are under the direction of a licensed physical therapist.

(17) (c) Physician - a doctor of medicine, osteopathy, dentistry or podiatry legally authorized to practice medicine, surgery, dentistry or podiatry in the state pursuant to Chapter 458, 459, or 466, or 461 R.S.

(18) (d) Plan of Treatment - written instructions signed by the attending physician for the provision of health care or treatment by a licensed nurse, or by a licensed physical occupational or speech therapist to a patient in the home.

(19) Quality Assurance - a system of reviewing and evaluating the appropriateness and effectiveness of patient services and correction of deficiencies.

4934 Professional Nurse - a registered nurse who is currently licensed in the state performing any act requiring substantial specialized knowledge, judgment and nursing skills based upon the principles of psychology, psychotherapy, physical and sexual sciences in the application of the nursing process.

4944 Practical Nurse - a currently licensed graduate of an approved school of practical nursing performing selected acts including the administration of treatment and medication in the care of the sick, injured or infirm, the maintenance of health and prevention of illness of others under the direction of a registered nurse.

(20) Speech Pathologist - a person licensed to practice speech pathology or audiology pursuant to the provisions of Section 468, Part II, R.S.

(21) (a) Subdivision - a component of a multi-function agency which independently meets the minimum standards for licensure.

4974 Field office - one within the county of the parent agency which shares administration and supervision and support services. The parent agency would be included in the single license.
§ 464.001 License Required. Before any entity shall either directly or indirectly operate a home health agency under Chapter 400, Part III, F.S., it shall make application for and receive a license from the Department, which shall be based upon compliance with all applicable laws, rules, regulations, and codes as evidenced by a signed application and upon the result of a survey conducted by Department representatives. A license shall not be required for any facility specifically exempted in Chapter 400, Part III, F.S.

1. The license shall be displayed in a conspicuous place inside the agency and shall be valid only in the hands of the applicant. Sale of a licensed agency, assignment, lease or other transfer, voluntary or involuntary, shall require relicensure by the new owner prior to taking over the operation.

2. In the event of change of ownership of the agency, the new owner shall submit at least 30 days prior to the effective date of the change an application for a new license.

If the agency is being leased, a copy of the lease agreement.
shall be filed with the application request of the Department that requested inspections be made and shall accompany or cause to be submitted a new application for licensure.

(3) The Department will provide consultative services, as feasible possible to agencies to assist in attaining and maintaining compliance with licensure standards.

(4) When an agency is leased by the owner to a second party for operations, said second party shall apply to the licensing agency for a new license. A copy of the lease agreement or certified statement showing which party is to be held responsible for the organization and operation of the agency shall be filed with the application for licensure.

Specific Authority: 400.497, 400.505 F.S.

Law Implemented: 400.467 and 400.477, F.S.

History: New 4-19-76. Previously numbered 10D-68.03. Amended

10D-68.004 Licensure Procedure. Licenses, issued by the Department to operate Home Health Agencies, will be based upon the results of a survey conducted by Department representatives to determine compliance with the requirements of Chapter 400, Part III, 88 F.S. and with these rules. A license shall not be granted to anyone under 18 years of age, or one who uses illegal drugs or is impaired by excessive use of alcohol or medicinal drugs a drug or abusive drug, or to anyone who cannot furnish satisfactory character references and evidence of financial responsibility.

(1) Initial licensure - new operation or change of licensed operator. Applicants for an initial license to operate a home health agency shall submit, in duplicate, an application on Form 435 -- 95 Application for Licensure, Home Health Agency, which is incorporated by reference, provided by the Department, which shall include:

(a) All of the information required by Section 400.471, F.S.

(b) Name of agency, address and telephone number.

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(1) Name of owner or licensee, address, and telephone number.
(2) License fee $500.00.
(3) Certificate of Need for agencies seeking certification in the Medicare program only.
(4) Ownership control and type.
(5) Services provided directly and by arrangement.
(6) Geographic area served.
(7) The name of the agency's administrator and the name and license number of currently employed in office staff by category, including licensed physicians, registered nurses, licensed practical nurses, other licensed employees and the number of aides, homemakers, companions or sitters and other personnel assigned to home health services work.
(8) Such additional information reasonably related to the above which the Department determines is necessary in order to act upon the application.
(9) A license, unless sooner suspended or revoked, shall automatically expire one year from the date of issuance and shall be renewable annually.
(10) Renewal of license. Applicants for renewal of a license to operate an agency shall submit an application on DHSS Form 635 -- 95 Application for licensure, Home Health Agency, which is incorporated by reference provided by the Department, which shall include:
(a) All of the information required by paragraph (1) above.
(b) The application for license shall be submitted to the Department on forms prescribed by the Department. The application shall be accompanied by a license fee in check or money order payable to the Department in the amount of one hundred dollars ($100-00-00) as part of which is recoverable. A statement from the accredited health planning council attesting to the need for a home health agency shall be obtained by the Department prior to issuing a license. Counties or municipalities applying for license under Chapter 4004 Part 137 P. S. L. are exempt from payment of license fee.
Separate insurance applications and fees for operation of an agency shall be submitted whenever the agency's services are operated outside of the county of the parent agency or operate as autonomous subdivisions.

Licensing shall expire one year from the date of issuance.

Applications for reissuance shall be submitted annually at least 90 days prior to the expiration date appearing on the currently held license.

The application for license shall be executed under oath and contain the following:

1. The name of the agency; mailing address; its location and descriptive data.

2. Ownership - The name and address of the owner or the agency; if a partnership or trust; the name and address of the president; vice president; secretary; and treasurer, and directors of the entity where profit or non-profit shall be shown.

3. The name and address of the applicant.

4. The name of the agency's administrator and the name and license number of currently employed licensed staff; licensed physicians, registered nurses, licensed practical nurses, other licensed employees, and the number of aides, attendants and other personnel assigned to home health services work.

5. A statement, together with such other additional evidence as may be specifically required by the Department, that the ownership possesses sufficient funds to operate the agency in accordance with Chapter 4067, Part III, FDS and all rules contained herein.

(b) All of the information required by paragraphs (1), (a), (b), (c), (d), (f), (g), (h), and (i) above.

(f) A conditional license may be issued to applicants against whom denial, revocation or suspension action is pending
at the time of license renewal, effective until final disposition of such proceedings by the Department.

Specific Authority 400.497, 400.503 P.S.

Law Implemented 400.471, 400.477, P.S.

History New 4-19-76. Previously numbered 100-68.04.

Amended

100-68.05 Prohibited Acts.

Specific Authority 400.497 P.S.

Law Implemented 400.497 P.S.

History New 4-19-76, Repealed

100-68.06 Right of Inspection.

Specific Authority 400.497 P.S.

Law Implemented 400.484 P.S.

History New 4-19-76, Repealed

100-68.07 Existing Home Health Agencies.

Specific Authority 400.497 P.S.

Law Implemented 400.461(2) P.S.

History New 4-19-76, Repealed

100-68.008 Scope of Services.

In all health care cases, the agency shall directly provide case management by a registered nurse to determine type, appropriateness, and adequacy of requested services including at a minimum an initial home visit for assessment of the patient's needs and development of the patient care plan as described in section 68.019 within 48 hours of the start of service.

Professional nursing and any other therapeutic services at home health aide services; at least one of which shall be provided directly. The agency's objectives shall state explicitly what services will be provided directly and what services will be provided under arrangements.
(2) The agency may provide other home health services as stated in LDR-40-002(2).

(3) The agency's objectives shall state explicitly what services will be provided and designate whether these services are provided directly by agency employees or under arrangements.

(4) Any change of services shall be reported to the Department within 30 days.

(5) Each agency shall submit an annual report to the Department within 90 days after the close of the agency's fiscal year which includes the following information:

(a) Total number of admissions and discharges of persons receiving services directly.

(b) Total number of persons receiving services directly from each individual discipline, including home health aides and homemakers.

(c) Total number of visits provided directly by each individual discipline, including home health aides and homemakers.

(d) Total number of admissions and discharges of persons receiving services under arrangements.

(e) Total number of persons receiving services under arrangements from each individual discipline, including home health aides and homemakers.

(f) Total number of visits provided under arrangements by each individual discipline, including home health aides and homemakers.

(5) Services provided under arrangements shall be through a written agreement which includes but is not limited to the following:

(a) Services to be provided.

(b) Provision for adherence to all applicable agency policies and personnel requirements.

(c) Designation of full responsibility for agency control over contracted services.

(d) Procedures for submitting clinical and progress notes.
(e) Charges for the contracted services.
(f) Evidence of liability and insurance coverage.
(g) Period of time in effect.
(h) Date and signatures by appropriate authorities.

Specific Authority 400.497, 400.505 P.S.
Law Implemented 400.497 P.S.
History New 4-19-76 Previously numbered 100-68.18

Amended

100-68.009 Personnel Policies. Administrative. The agency shall have written personnel administrative policies and practices to ensure the provision of safe and adequate care of the patient and shall show evidence of insusability insurance.

(i) Personnel policies available to all full and part-time employees shall include but not be limited to the following:

(a) Wage rates, hours of work, vacation and sick leave.

(b) Requirement for a pre-employment statement from a physician that the employee show no evidence of a communicable condition which would jeopardize the health of any person under care at the facility. Those employees not known to be tuberculin reactors shall provide documentation that they have had a tuberculin skin test within the past 6 months. Positive reactors to a tuberculin skin test shall provide documentation of adequate preventive therapy or the results of a chest x-ray taken within the past 6 months. Physical examination and a periodic physical examination at least every 2 years. Physical examination and a periodic physical examination at least every 3 years.

(c) Plan for orientation of all health personnel to the policies and objectives of the agency.

(d) Job descriptions for all employees.

(e) Annual performance evaluation for all employees.

(f) Compliance with requirements of Title VI of the Civil Rights Act of 1964.

(g) Personnel folders for all employees which shall include name and address of employee, social security number, date of birth, name and address of next of kin or -12-
guardian, the description, evidence of qualifications, statements of previous experience, licenses and/or registration if applicable, contracts if applicable, and dates of employment and separation from the agency and reason for separation.

Specific Authority 400.497, 400.501 F.S.

Law Implemented 400.497 F.S.

History New 4-19-76 Previously numbered 100-58.09

Amended
100-58.010 Administration. Personnel

The administrator of the agency personnel employed shall have the following qualifications and responsibilities:

(1) Be a licensed physician, or registered nurse, or have training and experience in health service administration and at least 1 year of supervisory or administrative experience in home health care or related health programs.

(2) The executive director shall be a full-time employee with at least three years experience with a health agency in an executive or supervisory capacity and have the following responsibilities on a full-time basis:

(3) The administrator director shall be familiar with the rules of the Department and maintain them in the agency.

(4) The administrator director shall be responsible for familiarizing the employees with the law and the rules of the Department and shall have copies of the rules available for their use.

(5) The administrator director shall be responsible for the total operation of the agency.

(6) The administrator director shall be responsible for the completion, keeping and submission of such reports and records as required by the Department.

(7) The administrator director shall designate an authorized representative to serve during absences a professional employee to be has.

(8) The administrator director shall maintain a current organizational chart to show lines of authority to the patient level.
The director shall clearly identify and make public services provided by the agency and the geographic area on which these services are available.

(3) The administrator shall maintain an office facility for the agency which is large enough for efficient staff work, adequately equipped, and which provides a safe working environment, meeting local ordinances and fire regulations.

(4) The administrator shall assure the provide for orientation of new staff, and opportunities for continuing educational experience for the staff regularly scheduled in-service education programs.

Specific Authority 400.497, 400.505 F.S.
Law Implemented 400.461(2), 400.471, 400.497(2) F.S.
History New 4-19-75 Previously numbered 100-63.10
Amended 10D-68.211 Nursing Director Supervising Nurse

(1) The nursing director supervising nurse shall be a graduate of an approved school of nursing and currently be registered in the state with at least 1 year of satisfactory nursing supervisory or administrative experience preferably in community health nursing and have the following responsibilities on a full-time basis. The nursing director supervising nurse shall be an employee of the agency and may also be the administrator director in an agency with less than 10 health service personnel.

(a) The nursing director supervising nurse shall be accountable for supervise all registered nurses, licensed practical nurses and home health aides staff.

(b) The nursing director supervising nurse shall insure that the professional standards of community nursing practice are maintained by all nurses providing care.
(1) The nursing director supervising nurse shall be responsible for maintaining and adhering to agency procedure and patient care policy manuals.

(4) The supervising nurse shall be responsible for the direct supervision of no more than fifteen full-time nursing service personnel. When full-time equivalents are used in the care of part-time personnel, the actual number of persons supervised shall not exceed eighteen (18).

(2) In the event the administrator agency designated is not a health professional, the nursing director supervising nurse shall, in addition to the above:

(a) Establish service policies and procedures in compliance with state health statutes and rules.

(b) Employ and evaluate nursing personnel.

(c) Coordinate patient care services.

(d) Set or adopt policies for, and keep records of criteria for admission to service, case assignments and case management.

(5) Prepare and maintain a schedule of those cases to be brought to the utilization review committee.

(6) Conduct selective program evaluations to improve deficient services and develop and implement plans.

(3) The nursing director shall establish and conduct a quality assurance program which assures:

(a) Case assignment and management is appropriate, adequate, and consistent with the patient care plan, medical regimen, and patient needs.

(b) Nursing services are consistent with professional community health nursing standards.

(c) Nursing and other services provided to the patient are coordinated.

(d) All services and outcomes are completely and legibly documented, dated and signed in the clinical service record.
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Law Implemented
400.461(2), 400.462(3)(a), 400.497(1),
400.497(2) 400.497(4) F.S.
History
New 4-19-76 Previoulsy number 100-68.11.
Amended
100-68.212 Registered Staff Nurse

(1) The registered staff nurse shall be a graduate of an approved nursing school and currently be registered in the state preferably with an least one 4th year of satisfactory nursing experience and have the following responsibilities:

(a) The registered nurse is the case manager. Case management shall include initial assessment of the patient and family for appropriateness of and acceptance for home health services, establishment and periodic review of the plan of care, implementation of medical treatment orders, referral, follow-up, provision and supervision of nursing care, coordination of services given by other health care providers, and documentation of all activities and findings.

(b) The staff nurse shall have the responsibility for observation, assessment, nursing diagnosis, care and health teaching of the ill, injured or infirm, and the maintenance of health and prevention of illness of others.

(c) The registered staff nurse shall be responsible for the maintenance of a clinical record for each patient receiving care.

(d) The registered staff nurse shall assure that progress reports are made to the attending physician about patients under her care when the patient's condition changes or there are deviations from the plan of treatment, or at least every 60 days.

(e) The staff nurse may make home health aide assignments and supervise the aide in the home.
444 The staff nurse may administer medications and
assessments as prescribed by a physician licensed in the state.

(2) The registered nurse may assign selected portions
of patient care to licensed practical nurses and home health
aides. In such circumstances, the registered nurse maintains
responsibility for the care given. Supervisory visits shall be
made to the patient's residence.

Specific Authority 400.497, 400.505 F.S.

Law Implemented 400.461(2), 400.462(1)(a), 400.497(1),
400.497(2) 400.497(5) F.S.

History New 4-19-76 Previously numbered 100-68.17
Amended 100-68.011 Licensed Practical Nurse.

(1) The licensed practical nurse shall provide assigned
nursing care under the direction of a registered nurse be a
graduate of an approved school of practical nursing and be
currently licensed in the state with at least 1 year preferably
of satisfactory nursing experience and

(2) The licensed practical nurse shall have the following
responsibilities:

(a) The licensed practical nurse shall preparing and
recording clinical notes for the clinical record.

(b) The licensed practical nurse shall reporting any
changes in the patient's condition to the case manager
her immediate supervisor with the report documented in the
clinical record her clinical notes.

(c) The licensed practical nurse may performing
assigned selected acts, including the administration of
treatments and medications, in the care of the patient. #48;
insured or infirm; the maintenance of health and prevention of
illness of others under the direction of a registered
professional nurses.

Specific Authority 400.497, 400.505 F.S.

Law Implemented 400.461(2), 400.462(1)(a), 400.497(1),
400.497(2) F.S.

History New 4-19-76 Previously numbered 100-68.17
Amended 1-31-86.
130-68.014 Home Health Aides.

(1) The home health aide shall have training in those supportive services which are required to provide and maintain bodily and emotional comfort and to assist the patient toward independent living in a safe environment. If the aide receives training through a vocational school, licensed home health agency, or hospital, the curriculum shall be documented. If training is received through the agency, the curriculum shall consist of at least 40 hours which shall include but not be limited to: six 4-hour hours of introduction to the home health services program, role of the aide, and differences in families; six 4-hour hours of instruction relating to nutrition, food and household management; twenty-four 4-hour hours of instruction relating to personal care services, assessment and six 4-hour hours of instruction relating to ethics and conduct, personal hygiene, agency policies, and reports and records. Personal care activities shall be taught by a registered professional nurse. When prior training is not equivalent to the minimum herein described, the necessary supplementary training must be provided and documented.

(a) Agencies shall have 1 year from the adoption of this rule to meet the training requirements.

(b) Those aides who are employed on the date of the adoption of this rule and who have had at least 1 year of experience with a licensed agency shall be exempt from the training requirement.

(2) Responsibilities of the home health aide shall include but not be limited to:

(a) The home health aide shall perform only those personal care activities contained in a written assignment by a health professional employee which include assisting the patient with personal hygiene, ambulation, eating, dressing, and shaving.

(b) The home health aide may perform other activities as taught by a health professional employee for a specific patient. These include and are limited to: assisting with the
change of a colostomy bag, shampoo, reinforcement of dressing, assisting with the use of devices for aid to daily living, for example, a walker or wheelchair, assisting with prescribed range of motion exercises which the home health aide and the patient have been taught by a health professional employer, assisting with prescribed ice cap or collar, doing simple urine tests for sugar, acetone or albumin, measuring and preparing special diets, intake and output.

(c) The home health aide shall not change sterile dressings, irrigate body cavities such as an enema, irrigating a colostomy or wound, perform a gastric lavage or gavage, catheterize a patient, administer medications, apply heat by any method, care for a tracheostomy tube, nor any personal health service which has not been included by the registered professional nurse in the patient care plan.

(d) The home health aide shall keep records of personal health care activities.

(e) The home health aide shall observe appearance and gross behavioral changes in the patient and report to the registered professional nurse.

(f) The home health aide patient services shall be evaluated by a health professional in the patient's home as frequently as necessary to assure safe, adequate care or at least every 3 months.

(g) The home health aide patient services shall be evaluated by a health professional staff at least every 6 weeks either with the aide present or absent in the home.

(h) The agency shall maintain a ratio of at least one health professional employee for to every five (5) non-professional persons providing health services when full-time equivalents are used in the case of part-time non-professional persons providing health services, the actual number of such personnel supervised shall not exceed 62.

Specific Authority 400.497, 460.505 P.S.

Law Implemented 400.462(3)(c), 400.497(1), 400.497(2) P.S.

History New 4-19-76. Previously numbered 100-68.14

Amended
100-68.215 Physical Therapist and Physical Therapy Assistant.

1. The physical therapist shall be a graduate of an approved school, currently licensed and registered in the state with at least 1 year of experience in physical therapy and have the following responsibilities:

   (a) The physical therapist shall provide physical therapy services as prescribed by a physician which can be safely provided in the home and assisting the physician in evaluating patients by applying diagnostic and prognostic muscle, nerve, joint and functional abilities tests.

   (b) Providing physical therapy services to assist patients to relieve pain, develop or restore function and maintain maximum performance using physical agents such as exercise, massage, heat, water, light and electricity.

   (c) Observing, recording activities and findings in the clinical record and reporting to the physician the patient's reaction to treatment and any changes in the patient's condition.

   (d) Instructing the patient and family in care and use of physical therapy wheelchairs, braces, crutches, canes and prostheses and orthotic devices and treatments as indicated.

   (e) Instructing other health team personnel including, when appropriate, home health aides and family members in certain phases of physical therapy with which they may work with the patient.

   (f) Instructing the family on the patient's total physical therapy program.

2. Physical therapist assistant. The physical therapist assistant shall be a graduate of an approved school giving a course of not less than two 44+ years for physical therapist assistant and be currently licensed in the state with at least 1 year of experience under the supervision of a licensed physical therapist. Responsibilities shall be directed by a licensed physical therapist.
Specific Authority 400.497(2), 400.505 F.S.

Law Implemented 400.461(2), 400.461(3)(b), 400.497(3)
400.497(2) F.S.

History New 4-19-76 Previously numbered 100-68.15
Amended

100-68.016 Speech Pathologist

(1) The speech pathologist shall be a graduate of an approved school, currently licensed in the state and have the following responsibilities:

(a) The speech pathologist shall assisting the physician in evaluation of the patient to determine the type of speech or language disorder and the appropriate corrective therapy.

(b) Providing rehabilitative services for speech and language disorders.

(c) Recording activities and findings in the clinical record and reporting to the physician the patient’s reaction to treatment and any changes in the patient’s condition.

(d) Instructing other health team personnel and family members in methods of assisting the patient to or improve and correct speech disabilities.

Specific Authority 400.497(2), 400.505 F.S.

Law Implemented 400.461(2), 400.462(3)(b), 400.497(3)
400.497(2) F.S.

History New 4-19-76 Previously numbered 100-68.15
Amended

100-68.017 - Occupational Therapist and Occupational Therapy Assistant

(1) The occupational therapist shall be a graduate of an approved school, currently licensed in the state with at least 1 year of experience in occupational therapy and have the following responsibilities:

(a) The occupational therapist shall providing occupational therapy services as prescribed by a physician which can be safely provided in the home and assisting the physician in evaluating the patient’s level of function by applying diagnostic and prognosis procedures.
b) Guiding the patient in his use of therapeutic creative and self-care activities for the purpose of improving function.

c) Observing, recording activities and findings in the clinical record and reporting to the physician the patient's reaction to treatment and any changes in the patient's condition.

d) Instructing the patient, family members and other health team personnel including when appropriate, home health aides and family members in certain phases of occupational therapy in which they may work with the patient.

2) Occupational therapy assistant. The occupational therapy assistant shall be a graduate of an approved program for occupational therapy by the American Occupational Therapy Association; shall have a minimum of 2 months of student field work experience, shall be currently licensed in the state; and have 1 year of experience as an occupational therapy assistant under the supervision of a licensed occupational therapist.

Responsibilities shall be those of assisting the licensed occupational therapist in an occupational therapy program.

Specific Authority 400.497(2), 400.505 R.S.

Law Implemented 400.461(2), 400.462(3)(b), 400.497(1)

400.497(2) R.S.

History New 4-19-76 Previously numbered 100-60.17 Amended

100-68.018 Medical Social Worker

444 The medical social worker shall be a graduate of an approved school with 1 year of experience in social services and have the following responsibilities.

433 444 The medical social worker shall assisting the physician and other members of the health team in understanding significant social and emotional factors related to the patient's health problems.

22 444 Assessing the social and emotional factors in order to estimate the patient's capacity and potential to cope with problems of daily living.
(1) **Helping the patient and his family to understand, accept and follow medical recommendations and provide services planned to restore the patient to optimum social and health adjustment within his capacity.**

(2) **Assisting patients and their families with personal and environmental difficulties which predispose toward illness or interfere with obtaining maximum benefits from medical care.**

(3) **Utilizing resources, such as family and community agencies, to assist the patient to resume life in the community or to learn to live within his disability.**

Specific Authority 400.497(2), 400.505 P.S.

Law Implemented 400.461(2), 400.462(3)(c), 400.497(1) 400.497(2) P.S.

History New 4-19-76 Previously numbered 100-68.19 Amended 100-68.019 Homemaker.

(1) The homemaker shall have at least 16 twenty forty-four hours of training in topics related to human development and interpersonal relationships, nutrition, marketing, food storage, use of equipment and supplies, planning and organizing of household tasks and principles of cleanliness and safety and have the following responsibilities:

(a) The homemaker shall Maintaining the home in an optimum state of cleanliness and safety depending upon family resources.

(b) The homemaker shall Performing the functions generally undertaken by the natural homemaker, including such duties as preparation of meals, laundry, shopping and care of children.

(c) The homemaker shall Reporting to the appropriate supervisor any incidents or problems related to her work or to the family.

(d) The homemaker shall Maintaining appropriate work records.

(2) The homemaker shall be supervised in the home by the appropriate supervisor at least once every 3 months a month.
(1) Agencies shall have 1 year from the adoption of this rule to meet the training requirements. Those homemakers who are employed on the effective date of this rule and who have had at least 1 year of experience under supervision shall be exempt from the training requirements.

Specific Authority 400.497, 400.505 R.S.

Law Implemented 400.461(2), 400.462(3)(c) 400.497(2) R.S.

History 4-19-76 Previously numbered 100-68.19
Amended 100-68.020 Acceptance of Patients.

(1) Acceptance of patient and discharge policies shall include but not be limited to the following:

(a) No person shall be refused service because of age, race, color, sex or national origin.

(b) When a person is accepted for health service, there shall be a reasonable expectation that the services can be provided persons medically necessary dietary physical or social needs can be met adequately and safely in his residence.

(c) Persons shall be accepted for health service only upon a written plan of treatment established by the attending physician reduced to writing within eight (8) days.

(d) When medical treatments or medications are administered, physician's orders in writing which are signed and dated shall be included in the clinical record.

(e) When services are to be terminated, the person shall be notified of the date of termination and reason for termination which shall be documented in the clinical record. A plan shall be developed or a referral made for any continuing care indicated.

(f) Homemaker and companion services shall not be terminated until such time as the patient's family, physician and other professional persons providing care mutually agree or arrangements are made for continuing care.

Specific Authority 400.497, 400.505 R.S.

Law Implemented 400.461(2), 400.487(1), 400.497(4), 400.497(5) R.S.

History New 4-19-76 Previously numbered 100-68.20
Amended
100-68.02 Patient Care Plan. Plan of Treatment.

(1) A plan of treatment shall be established and reviewed by the attending physician in consultation with agency staff involved for all patients receiving nursing care or treatment, or physical, occupational or speech therapy. Nursing care or treatment in this instance means technical activities performed by a licensed nurse to provide for the comfort, safety, treatment and rehabilitation of the patients.

(2) The plan of treatment shall be reviewed at such intervals as the severity of the patient's illness requires, but in any instance, at least every 60 days and shall include but not limited to the following:

(a) Diagnosis.
(b) Activities permitted when indicated.
(c) Diet where indicated.
(d) Medication, treatments, and equipment required.
(e) Dated signature of physician.
(f) Types of services and equipment required.
(g) Specific frequency of visits such as two times a week or three times a week, etc.

(2) The registered agency nurse who is the case manager, other health professional staff and physician when appropriate shall collaborate in developing one patient care plan for each patient receiving home health services and the plan may be included in the clinical notes and shall include, but not be limited to the following:

(a) Source of referral.
(b) Listing of drugs and treatments prescribed name of by the physician, if physician is different from doctor signing the plan of treatment.
(c) Statement of patient or family problems.
(d) Statement of ability of patient and family to provide interim health services.
(e) Assessment of the patient needs.
A list of specific service goals with plans for implementation including at a minimum:

1. Level of workers who will provide the care.
2. Frequency of home visits to provide direct care and case management.
3. Frequency of supervisory visits when non-professional personnel provide direct care.

(q) Date and signature of the nurse case manager agency staff developing the plan.

(b) Periodic reassessments and revisions of the plan as the condition of the patient changes, dated and signed by the case manager each professional providing care.

Specific Authority 400.497, 400.505 P.S.
Law Implemented 400.497(1), 400.497(5) P.S.
History New 4-19-76; Previously numbered 100-68.21
Amended 100-68.022 Clinical Records.

The agency shall maintain a clinical record for every person receiving home health services which shall include, as appropriate, but not be limited to the following:

(1) Identification sheet containing name, address, telephone number, date of birth, sex, agency case number if used, next of kin or guardian.

(2) Permission to release information dated and signed by patients, family or guardian when applicable.

(3) Plan of treatment.

(4) Clinical and service notes, signed and dated by the staff member providing the service which shall include:

(a) Initial assessments and progress notes with changes in the person's condition.

(b) Patient Care Plan.

(c) Services rendered.

(d) Observations.

(e) Instructions to the person and family.
(5) Home visits to patients for supervision of non-professional workers. Home health aide when applicable.

(6) Reports Evidence of case conferences.

(7) (d) Evidence of reports to physicians.

(8) (e) Termination summary including:
   (a) Date of first and last visit.
   (b) Total number of visits or hours by discipline.
   (c) Reason for termination of service.
   (d) Evaluation of established goals at time of termination.
   (e) Condition of the patient on discharge.
   (f) Disposition of the patient.

Specific Authority 400.497, 497.505 P.S.

Law Implemented 400.497(5) P.S.

History New 4-19-76. Previously numbered 10D-68.12
Amended 2-2-77,
100-68.23 Utilization Review.

Specific Authority 400.497(5) P.S.

Law Implemented 400.487(1),(2), 400.491,400.497(5) P.S.

History New 4-19-76. Repealed,
10D-68.314 Administration of Drugs and Biologicals.

(1) The agency shall have policies governing the administering of drugs and biologicals.

(2) The policies which shall include but not be limited to the following:
   (a) All orders for medications to be given by the agency health professional staff shall be dated and signed by the attending physician.
   (b) All orders for medications shall contain the name of the drug, dosage, frequency, method or site of injection, and permission from the physician if the patient and/or family are to be taught to give the medication.
   (c) All verbal orders for medication or change in medication orders shall be taken by a registered nurse the
state health professionals and reduced to writing and signed

with title by the physician within 14 days.

Nurse shall not give drugs except for an
emergency but including syringes, needles, commutation, array and
agency approved drug for use should the patient have a severe
drug reaction.

Experimental drugs, sera, allergic
desensitizing agents, penicillin or any other potentially
hazardous drug shall not be given without the fully informed
consent of the patient or family. The nurse administering such
drugs shall have an emergency plan and whatever drugs and/or
devices are appropriate in reversal of drug reaction.

Specific Authority 400.497, 400.505 F.S.
Law Implemented 400.487(1), 400.497(3) 400.497(5) F.S.
History New 4-19-76 Previously numbered 100-68.24
Amended
100-68.275 Companion or Sitter.

11) The companion or sitter shall have the following
responsibilities performed under the supervision of a
professional employee of the agency:

(a) Providing companionship for the patient.
(b) Providing escort services such as taking the
patient to the doctor.
(c) Providing light housekeeping tasks such as
preparation of a meal or laundering the patient's personal
garments.
(d) Maintaining a chronological written record of
services.
(e) Reporting any unusual incidents or changes in the
patient's behavior to the registered nurse.

12) The companion or sitter shall not perform any hands on
personal health care services.

13) The agency shall insure that companions or sitters
understand the needs of the patients to which they are assigned.
recognize those conditions which need to be reported to the registered nurse.

Specific Authority 400.497, 400.495 P.S.

Law Implemented 400.462(1), 400.497(1), 400.497(2) P.S.

History New.

100-68.026 Penalties

(1) The department shall set and levy a fine not to exceed $500.00 for each violation of the provisions of this chapter or of any minimum standards or rules promulgated pursuant to Chapter 400. Part III, Florida statutes.

(2) In determining if a fine is to be imposed and in fixing the amount of the fine to be imposed, if any, for a violation, the department shall consider the following factors:

(a) The gravity of the violation, including the probability that death or serious physical or emotional harm to a patient will result or has resulted, the severity of the actual or potential harm, and the extent to which the provisions of the applicable statutes or rules were violated.

(b) Actions taken by the agency to correct violations.

(c) Any previous violations.

(d) The financial benefit to the agency in committing or continuing the violation.

(3) The failure to file a timely application shall result in an administrative fine charged to the agency in the amount of $100.00 per day, each day constituting a separate violation. In no event shall such fine aggregate more than $3,000.00.

Specific Authority 400.497 P.S.

Law Implemented 400.474 P.S.

History New.
May 9, 1987

The Honorable John Melcher
Chairman Special Committee on Aging
United States Senate
Washington, DC 20510-6400

Dear Senator Melcher:

Thank you for according me at your recent hearing the opportunity to share with you my experiences with Federally funded and privately funded home care. I'm submitting the following as part of the record. During the hearing you heard testimony from several people a testimony of the lack of measures to assure the quality of in-home care. These problems range from costly over-utilization and inappropriate Medicare service provision to unacceptable physical and mental neglect and abuse. These problems are continual and the need for a solution is urgent.

It is my fear that your search for this solution might create further paper documentation of that standards might be seen as an answer to these problems. There is no "paper review" that can assure frail ill people will receive the care that is intended with our Medicare dollars. There is no documentation that can prevent over serving and inappropriate service to these patients.

There must be an independent network of local agencies which can objectively monitor the care on-site. This network must be responsible for assessing the needed care and monitoring this care in the home as long as the home health agency is involved. This network, which must be able to authorize and control what care will be reimbursed, must also be national and uniform so all older Americans have equal access to quality care.

Since the Aging Network - that is, the nation's Area Agencies on Aging - do not deliver services directly, they are in a singularly advantageous position on behalf of the Federal government and the nation's elders to perform this service. If the Aging Network is not chosen to monitor in-home care for this, it will be necessary to duplicate it to provide solid quality assurance. The Aging Network is in place and very able to accept the responsibility for this so desperately needed function.

Care Management through Michigan's Region IV AAA has been serving this purpose for four years. We have learned a great deal about monitoring these services during this time, and we offer this experience to assist you in developing such a system for this monitoring.

Thank you again for your deep concern for vulnerable older persons. If I can be of any further services, please do not hesitate to let me know.

Best wishes,

Barbara Lutton, RN
Supervising Nurse
Care Management Program

BL:je
STATEMENT OF ALBERT D. BUFORD, III, Executive Director, Center for the Public Interest, Los Angeles, California.

MR. BUFORD: I would like very much to thank this Committee, and particularly its Chairman, for the invitation to submit testimony at this time of reauthorization of the Older Americans Act.

Since the Model Project days of the mid-1970's, staff now associated with the Center for the Public Interest have labored to equip non-lawyers with the knowledge and skills to advocate on behalf of the frail, older American. At the center of our training has been a concern for the legal issues inherent in perfecting Medicare benefits — that is, a concern for educating advocates to the Medicare law and how the Medicare system works in the everyday world.

In short, our Center has long believed that public benefits problems -- particularly Medicare problems -- can often be addressed if only the law is clearly explained, is clearly understood. We also believe that in most instances, a non-lawyer advocate can be taught the Medicare law, and thus taught how to advocate, using the law, for those who have been improperly denied Medicare benefits.

Accordingly, in 1985, the Center applied for and obtained grant monies to produce a video documentary training program for lay advocates. The focus of this documentary is Medicare-reimbursed home health care and skilled nursing home care. (A copy of this video has been submitted to this Committee for the record.) It is entitled simply, "Will Medicare Really Pay the Bill?"

In preparing for this video program, Center staff conducted an extensive survey of providers, consumer advocates, government officials and others -- all with an eye towards examining, in detail, how the Medicare claims process really worked. The vast majority of this inquiry focused on home health care. Several of our findings, we believe are quite relevant to this Committee:

1. Many times older persons are entitled to home health care reimbursement under Medicare, but often benefits are improperly denied such persons.

2. Although the Medicare law has not changed significantly, home health care benefits are being denied with increasing frequency. (Oklahoma home health care
providers estimate their reimbursement under Medicare at only two thirds of what it was a year ago.

3. The Waiver of Liability Rule which allows providers of home health care to be timely paid, also induces them to deny benefits which should be legally, rightfully awarded -- this by the threat of corporate liability for an overall award "error rate" in excess of $21/2%.

4. The government's own statistics confirm the error rate. The attached letter from the Health Care Financing Administration reveals that, when challenged on appeal, to an administrative hearing, the national average for reversing previous denials of coverage is fully 65% (sixty-five percent)! Another way to look at it is this way: with regard to home health care, Medicare is guilty of a 65% (sixty-five percent) error rate. Hence, the need for advocacy.

And, thus, we'd like to make a simple suggestion. It relates to advocacy under the Older Americans Act. Simply put, we believe it is time all of us admitted that the Medicare system which is in place today -- particularly as it relates to Medicare-reimbursed home health care -- is not a self-executing system. For the most frail, home health care coverage under Medicare is often elusive. Simply put, without the assistance of an advocate, often times the most frail among us stand no chance of gaining home health care coverage paid for by Medicare -- even when the law allows for extensive coverage for exactly these persons.

Therefore, we at the Center for the Public Interest commend this Committee for its attention to the plight of those who are frail and who have the need for nursing care in the home. We would like to remind the Committee that what is required, in order to obtain benefits which the Congress intended, however, is often the assistance of an advocate. We would also like to state that we believe that this advocacy is clearly envisioned within the Older Americans Act. Indeed, this is the type of "legal assistance" which the aging network ought to be about -- what the Act envisions. I am confident of this, in part, because I had the honor of serving as the first Project Director for such a lay advocacy training effort funded by Commissioner Fleming in 1976. But we believe that critical non-lawyer advocacy, conducted in
the front ranks has recently gone almost unnoticed. And we believe that it is time to provide advocates -- often non-lawyer, paid and volunteer advocates -- operating within the Older Americans Act network the technical support they deserve. In short, training and technical assistance for this network ought well be the focus of this Committee's concern, as well as that of the Administration on Aging, itself.

Our in-depth documentary asks the questions, "Will Medicare Really Pay the Bill?" In the home health care arena, without advocacy, the answer is often no. We believe the Medicare home health care system can be made to work. And we believe that the way to make it work, at least in part, is to recognize the local Older Americans Act advocates already about the process of Medicare advocacy. Then we believe it is important to give these persons advocacy tools, in the form of training materials and technical assistance.

Support for Older Americans Act legal advocacy in the field is not a new or novel concept. But in recent years, we believe both the Congress and the Administration have, perhaps, simply not been privy to the fine work of such non-lawyer advocates -- again, folks already operating within the senior centers, the nutrition sites, the case management programs. As long as Medicare's home health care benefit is dependent on advocacy, they more than any others, deserve our attention, indeed our help, in enhancing the good work which they have begun. Therefore, I hope that the legislative history surrounding this year's reauthorization will comment on, indeed encourage support of, Medicare home health care advocacy where it counts most -- in the front ranks -- in the Older Americans Act network itself.

I thank this Committee for their hard work and for the opportunity to share my concerns at this time of reauthorization.
Mr. Albert D. Buford, III  
Center for the Public Interest, Inc.  
Suite 414  
1800 North Highland  
Los Angeles, California 90028

Dear Mr. Buford:

This is in response to your November 18, 1986, Freedom of Information Act request for information concerning Medicare benefits.

It is our understanding that the Dallas Regional Office sent to you directly information pertaining to items one and three of your request. We were also informed that due to cutbacks in staff in the early 80's, Home Health Care statistics are not maintained.

The following is additional information relating to your request:

Question 2 The average number of Skilled Nursing Facility days reimbursed per spell of illness: Based on 1981 figures, which are the most complete SNF utilization measures available, the average number of days reimbursed per stay is estimated at 30 days nationally. Regional State data regarding this measure are unavailable.

Question 4 The amount of Medicare dollars expended for SNF care: For 1984, Medicare reimbursed over $21.6 million dollars for SNF care in the Dallas Region. The breakout shows-

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<thead>
<tr>
<th>State</th>
<th>Dollars</th>
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<tr>
<td>Dallas</td>
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<tr>
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<tr>
<td>Louisiana</td>
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<td>Texas</td>
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The following current statistics on appeals are based on Nationwide figures for fiscal year 1985:

<table>
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<tr>
<th>Part A Reconsiderations</th>
<th>Reversals (Full &amp; Partial)</th>
<th>% of Reversals</th>
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</thead>
<tbody>
<tr>
<td>30,929</td>
<td>1,503</td>
<td>17.8</td>
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<table>
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<tr>
<th>Part A (ALJ) Hearings</th>
<th>Reversals (Full &amp; Partial)</th>
<th>% of Reversals</th>
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<tr>
<td>1,238</td>
<td>805</td>
<td>65.0</td>
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</table>

There is no charge for processing this request because the chargeable costs do not exceed $3.00.

Sincerely yours,

Rosario Cirrinicone  
Chief, Freedom of Information Branch  
Office of Public Affairs
Senator John Melcher, Chairman
Senate Special Committee on Aging
U.S. Senate
Room SH 626
Washington, D.C. 20510

Dear Mr. Chairman:

On behalf of our client, the National Association of Companion Sitter Agencies and Referral Services (NACSARS), which is comprised of privately-owned, for profit referral services and agencies that specialize in companion and home care services for the elderly, long-terminfirmed and children, we would like to submit these comments to be included as a part of the April 27, 1987 Select Committee hearings entitled: "Home Care: The Agency of Indifference."

Mr. Chairman, the Senate Special Committee on Aging cannot review all aspects of the home care industry in these hearings and claim to reach conclusions on regulations and quality control without the input of privately-owned, for profit referral services and agencies comprised in NACSARS. In fact, this is the second example within the past year in both House and Senate committees of jurisdiction that NACSARS has been ignored in their repeated requests to appear before a congressional committee.

NACSARS members are greatly concerned that the witnesses appearing before the committee left the incorrect impression that individuals as providers, working as independent contractors, are unqualified, and dispensed poor quality of services to the clients. Nothing could be further from the truth. Every industry has its 'rotten apples', but to single out any part of the home-health industry and point to that part as the culprit does a disservice to the families who need a cost-effective means of meeting home-health needs.

For example, the National Association For Home Care's witness, Ann Hoot, in her prepared testimony before your committee's April 27, 1987 hearing, attacked individuals as providers and recommended the complete prohibition of independent employment of paraprofessionals using federal funds, citing as reasons poor care, abuse, lack of training and cost factors that result in the lowest cost provider being chosen under social services block grants and Title IV other than certified agencies who "cannot compete on a straight cost basis."

What is misleading to the Congress and the American people, is the impression this witness left that all independent contractors were somehow tainted with her example of abuse. She cited the example of an independent contractor aid who "was arrested and charged with arson, attempted murder, and fraud after she allegedly attempted to murder her client to cover-up stealing nearly $5,000 from him during the year she had cared for him." NACSARS does not condone abuse in the industry. Those guilty of crimes, whether they steal millions from Medicare and Medicaid funds or abuse their clients, should be punished. No one disagrees with that. What upsets NACSARS members around the country is the constant allegations by such groups as the NASC that all independent contractors are suspect as untrained, unprofessional and abusive to their clients. We maintain that one of the real reasons for this antagonism is economic rather than quality control.

NACSARS supports the statements of two witnesses appearing before the committee at the April 27, 1987 hearing. Charles Wells, Deputy Commissioner on Aging, Administration on Aging, said: "A discussion of home care services must recognize the important role of the non-agency individual contractor. The national long-term care channeling demonstration, a landmark ten-
state experiment supported by the department -- including AOA -- confirmed that high quality personal care services can be given by persons carefully recruited by family members through newspaper ads, neighborhood contacts, and friends.*

In addition, Jane Anderson, representing the National Association of Area Agencies on Aging said: "Standards, however, should not result in restricted access to care because of unavailability or costliness occasioned by the standards. Many area agencies on aging in rural areas, for example, have had to deal with the lack of providers in creative ways to see that the frail elderly could remain in their own homes. We are concerned that too stringent standards, dealing perhaps only with criteria for personnel, may result in restricted access to needed care. If standards focus only on quality, then cost savings both to public and private payors, and appropriateness are likely to suffer, both at the expense of the client as well as the home care industry."

NACASARS members are not Medicare-certified home health agencies, because Medicare regulations do not provide for direct reimbursement. However, independent contractors who are referred by NACASARS-member referral services provide their clients with quality, professional services at a much reduced cost, compared to other home health agencies. For example, in Connecticut the Medicare-certified agencies ranged last year in price for home health aides from $9.95 to $11.50 per hour, with a 4-hour minimum, while the independent contractors referred by NACASARS had a price of $6.20 per hour with no minimum. These cost-comparisons are similar throughout the country, and could have a significant impact on aggregate home health costs in the future.

NACASARS believes that the general public should be free to choose home-care providers, particularly if the care needed is minimal. Nurses registries and companion sitter agencies throughout the country can provide a much-needed service to the chronically ill, but essentially stable, individual by referring fully-screened personnel to work privately for then. The registries and companion sitter agencies can offer these services at very reasonable prices. Why should independent senior citizens, or families who care for the elderly at home, pay a higher price for skilled services and supervision in cases where none are required, much less wanted?

The more expensive skilled service agencies have the advantage of direct reimbursement of their fees by insurance or by Medicare (in some limited cases). This type of reimbursement is not available at present, nor probably in the near future, for private referral services and the independent contractors (i.e., nurses or sitters) who are referred by such referral services. A gap in society is developing, called a "no-care zone," where middle class Americans cannot afford the minimum services they need to remain independent.

Of critical importance is the need to keep the costs under control. We are especially concerned with those patients and their families who must pay for services themselves. Of particular concern is the patient requiring long-term care who is still maintained at home provided he or she gets outside assistance. Some of the NACASARS members have been referring independent contractors, who provide much assistance, for over twenty years. These problems will be magnified in the future by the sheer number of elderly citizens requiring services and by the changes in the regulations affecting health care.

With the growth of the total health-care industry, we have seen the number of providers increase, particularly franchised agencies; and we have seen the inevitable fight for the health-care dollar as each agency adjusted to change. Of major concern is our fear that the privately-owned referral services will be forced from the field despite the fact that they are successfully providing the custodial care at much lower rates, and at no government expense, than other agencies.

There is a need for long-term care to relieve the family of the "constant" care of their family members, and to permit workers to return to the market place. Intermittent care, such as provided by Medicare-certified agencies, does not meet the
need of the majority of our elderly citizens who most often may need both custodial care and skilled nursing.

The referral-service industry has been subjected to much criticism. Our critics indicate that the use of independent contractors, who are not supervised, leads to the possible abuse of the elderly. However, most of the time both family and physician supply supervision and instruction.

NACSARS submits that there is no more abuse here than in any other business, and that we are just as concerned about these issues as are other Americans. Nevertheless, we believe that it is more likely that these criticisms arise from a concern on the part of some to eliminate competition, regardless of the effect this would have on those who can least afford to lose low-cost services.

Questions have been raised during the hearing on quality of care and standards. Attached to these comments are a copy of the NACSARS Code of Ethics and Standards of Operation. While these are merely the first in a series of standards and ethics contemplated by NACSARS, they indicate a good faith effort to address quality of care issues within the referral-service industry.

One of the largest barriers to the ability of referral services to take affirmative action to improve or ensure the quality of care provided by the service-providers who have been referred, is the potential conversion of the status of such services providers from that of independent contractors to that of employees. If service-providers are considered employees, then the referral services would have to withhold income and social security taxes, pay unemployment taxes, pay workers compensation premiums, pay liability and malpractice premiums, and pay all the added administrative expenses associated with employees. Simply put, all referral services would have significant rate increases, and many would simply be put out of business.

The solution is to pass legislation that would permit referral services to provide quality care education and supervision of independent contractors without having the status of such independent contractors shift to that of employees. This would be best for both consumers (who would get quality care at continued low rates) as well as referral services.

Accordingly, we suggest that the Committee on Oversight:

1. Hold a hearing on non Medicare-medical reimbursement of private-sector home care providers, and focus at that hearing on 1) the cost saving aspects for families, the government and the insurance industry; and 2) protection of the independent-contractor status even when quality of care supervision is provided by referral services. NACSARS would be pleased to assist the committee with witnesses and information.

2. Develop legislation to encourage the use of independent contractors in the home-care area 1) through tax credits, tax savings, and expense deductions for the families, hospitals or other providers utilizing the services of NACSARS-type members; and 2) through protection of the status of such independent contractors.

We would like to assist the committee on these most important issues, and would welcome your action on our client's positions relative to cost savings and independent contractors in the home care area.

Sincerely,

John Chwat

Enclosure
CODE OF ETHICS

1. We will strive to maintain the integrity and quality control of our industry/profession.

2. We will support and protect the individual rights of our clients.

3. We will promote those activities which are primarily consumer oriented.

4. We will advocate quality health care services with a secondary emphasis on cost effectiveness.

5. We shall pursue those research and educational activities that will increase the knowledge of all NACSARS affiliates on a national level relating to changes and advances affecting our profession.

6. We will strive to educate and work in conjunction with those in politics in order to assist them in making effective decisions governing our industry.
STANDARDS OF OPERATION

1. Members will obtain and maintain licensure and/or certification according to state and federal guidelines established. Also, proper DDD bonding should be secured.

2. Referrals will be sent out in compliance with physician directives. In cases where such directives are not available, referrals will be governed by criteria in each State's Nurse Practice Act. When Nurses Aides are requested in a home, an RN evaluation of patient status will be completed within 48 hours of initiation of care to determine whether or not the services being requested are appropriate.

3. a) Placement of referrals will be determined and/or supervised by a Registered Nurse.
   b) Companion/Sitter referrals will not be permitted to perform duties within the scope of nursing and therefore, a Registered Nurse supervising the referrals will not be necessary. However, these such agencies are encouraged to seek consultation arrangements with a licensed Registered Nurse.

4. Nurses Aides referred shall be required to have an accredited Nurses Aide course in areas where available. Also, when state certification is obtainable, this shall be the criteria. In areas where neither of the above is available, one year experience under supervision in either a hospital or nursing home shall be the criteria for placement. In addition, it is preferable even with those individuals who have obtained state certification, to have a minimum of at least one year experience either in a hospital or nursing home under supervision.

5. All nurses and/or nursing assistants referred shall be currently licensed according to state regulation; also, CPR certificates shall be required in the areas where available. The agency shall be responsible for maintaining proper records of such licenses and certification.

6. References both work and character related should be actively pursued and acquired before any applicant shall be referred for services.

7. A working history shall be kept and maintained including client names, location and medical problems along with any positive or negative feedback relating to the individual's performance.
The Federal Council on the Aging is pleased to submit its recommendations for amending the Older Americans Act during the 1987 reauthorization period.

A rapidly increasing aging population and limited resources have presented us with unique challenges in attempting to meet the needs of older Americans. While most older persons are comparatively healthy and active, a significant number require varying degrees of supportive services in order to cope with the demands of daily community living. Families, neighbors, and the State and Area Agencies on Aging, as well as others involved with aging concerns and services, have responded to this wide diversity of need. It is of paramount importance, however, that the aging network continue to be supported and strengthened in order that it may meet the challenges of the future. The Council's recommendations reflect this support in calling for increased discretion for the network.

The Council has long held a special concern for the "frail elderly," those most vulnerable members of the aging population. Our current recommendations continue to emphasize this concern by addressing the issue of targeting resources to those in "greatest economic or social need." Older Americans who are minorities, low income, women, functionally impaired, live alone or live in rural areas are most likely to be or to become more vulnerable than other older persons and, therefore, should be targeted at the local level within the parameters of the circumstances and resources of the community.

The Council appreciates the support and concern provided to older Americans and presents these recommendations for your consideration and response.

Sincerely,

Ingrid C. Azvedo
Chairman

Enclosure
SUMMARY

The Federal Council on the Aging (FCA) urges the extension and reauthorization of the Older Americans Act (OAA) for a period of five years. While in complete support of the intent and purposes of the OAA, the FCA recommends a number of changes that will strengthen the purposes and objectives of this legislation and enhance services to older Americans.

The great diversity present in the aging population dictates a broad range of options in responding to and defining the parameters of need of these individuals. As individual capacities and vulnerabilities are considered, it becomes apparent that resources must be better targeted to approach most effectively the differences in level of need. Resources are not unlimited and those with the greatest need must be of greatest concern.

Needs of individuals are most appropriately determined within the circumstances of the community in which they reside. Although it is possible to identify generally characteristics that may indicate vulnerability of an older individual, these separate characteristics will not apply in each and every community. Therefore, it is the responsibility of those in a position to understand the capacities and constraints of a community to define the needs to be addressed in that community.

The FCA encourages regular incremental increases of 5 percent to assure adequate funding levels for all the Titles of the OAA. Each of the components of the OAA is a vital part of the whole and none should be sacrificed if the needs of older Americans are to be addressed in an effective and comprehensive manner.

The Federal Council believes that contributions based on ability to pay should be an integral part of Older Americans Act programs. However, the Council feels strongly that means testing should not be used to establish eligibility or amount of contribution. The Council has learned that in several regions of the country a voluntary sliding fee scale has worked well for requested services.

The OAA was intended to stimulate the development of a comprehensive, coordinated approach to the diverse needs of the older population. The FCA believes that the coordination of programs and services of both the public and private sector is vital to improving the quality of our country's response to the concerns of our aging population. To take full advantage of all segments of the community, the Council has asked that some restrictions on for-profit organizations be removed from OAA language.
Congress has charged the Council with the responsibility to review and evaluate, on a continuing basis, Federal policies regarding the aging and programs and other activities affecting the aging. It is, therefore, incumbent upon the FCA to carefully examine the current issues regarding the reauthorization of the Older Americans Act. Aware of this responsibility, the Council has undertaken a review of the issues raised by the Administration, the national aging network and organizations, the private sector, other State and local governmental entities, and the general public.

The OAA has been amended ten times since its inception. Provisions of the original legislation were extended in 1967. The 1969 amendments strengthened the Title III community services programs and charged the State Agencies on Aging with Statewide responsibilities for planning, coordination, and evaluation of programs for older persons. The 1972 amendments created national nutrition programs and authorized grants to public and nonprofit sponsors for the development of congregate meal services. The creation of the Area Agencies on Aging was mandated by the 1973 amendments in addition to the creation of the National Information and Resource Clearinghouse for the Aging and the Federal Council on the Aging. Amendments made in 1974, 1975, and 1977 primarily extended the authority for continued program operation, and made a number of minor adjustments to the Act. The 1978 amendments further strengthened and expanded Title III of the Act by consolidating the social services, multipurpose senior center, and nutrition services portion of the Act. A separate Title, Title VI, authorizing grants for Indian tribes, was established. In addition, a separate authorization for home-delivered meals was made under Title III. Since the 1981 and 1984 amendments primarily extended the programs and made only minor changes, the 1987 reauthorization period is a time for careful review and amending to update the Act.

The following pages detail the Council's recommendations for amending the OAA in 1987. Some of the recommendations contain extensive rewording and redirection while other recommendations seek to strengthen existing language or to emphasize areas that the Council finds of particular importance.

**Title I**

Title I sets forth the objectives of the OAA. Ten broad goals are outlined toward giving older persons opportunities for participation in the full life of the community. These goals are: (1) an adequate income; (2) physical and mental health; (3) suitable housing; (4) all restorative services for those who require institutional care; (5) employment without age discrimination; (6) retirement in health, honor, and dignity; (7) participation in civic, cultural, and recreational activities; (8) effective community services; (9) benefit from research designed to sustain and improve health and happiness; and (10) freedom to plan and manage their lives.

Recent emphasis on increasing the efficiency and effectiveness of service provision dictates a systematic approach to the above listed goals and the development of a continuum of care concept. Long-term care no longer refers just to the institutional care of the chronically ill. There is now great concern with the prevention of institutionalization and with the provision of supportive services in the community to maintain the individual in the home for as long as is feasible.

1. **Policy**

The Council feels that one additional Title I objective should be added to deal with elder abuse and exploitation.

**Language Change**

Insert the following as item (11) under section 101.

(11) Freedom from abuse, neglect and exploitation in all aspects of daily living.
2. POLICY

With longevity resulting in more multi-generation families, the Council feels that Title I should enumerate services to and consideration for the family caregiver.

Language Change

(12) Support to family members and others providing voluntary care to those older citizens needing long-term services.

3. POLICY

The Council is aware that a more concise definition of the term "rural" is necessary as this has been an ongoing troublesome problem in the administration of the Older Americans Act.

Language Change

Insert the following as item (8) under section 102.

(8) The term "rural" should be determined in all matters of the Act as defined by the Bureau of the Census.

TITLE II

Title II establishes the Administration on Aging (AoA) within the Department of Health and Human Services (DHHS) as the principal agency for carrying out the purposes of the OAA and administration of the grant programs authorized under the Act. It is the part of the Act which discusses the establishment of the functional units necessary to implement the Act, including the Federal Council on the Aging.

Organizationally, the AoA is located within the Office of Human Development Services (OHDS) in DHHS. Congress intended that the AoA was to serve as an effective advocate on all Federal activities and matters related to the field of aging. With increasingly complex and enlarged programs impacting on the elderly, more demands and pressures are placed on the AoA to perform its advocacy, as well as program administration functions.

4. POLICY

The Council urges the Secretary of the DHHS, to provide the maximum support possible to the Commissioner on Aging in carrying out the mandates contained in the OAA. This includes the strengthening of the Commissioner’s decisionmaking authority, flexibility, and visibility within the Federal establishment and the aging network wherever and whenever possible and feasible.

Language Change

Delete from Section 201(a) the words in line 7 and line 9

"the Office of."

5. POLICY

Extending the reauthorization period to five rather than the customary three years reflects the refined state of this legislation. The Council feels the longer authorization period will allow for efficiency in program management. The Council also feels that a longer reauthorization period will allow for substantive changes without the trauma of total reauthorization.

To facilitate the five year authorization, the Federal Council recommends the following language change.

Language Change

Insert the phrase, "and such sums as may be necessary for the fiscal years 1988 through 1992" at the following places throughout the Act:
6. POLICY

The Council feels an important role in its responsibilities is to nurture interagency cooperation among the various Federal departments which oversee programs dealing with the elderly.

Language Change

Insert new paragraph under section 204(d).

(6) Act as coordinator to bring together and improve working relationships between all Federal Departments and agencies that deliver services or programs to older Americans.

7. POLICY

Given the demographics of aging, the Council feels that input from its members serving on advisory boards of these Federal agencies or departments listed in the Act's Sec. 203, could provide valuable gerontological information and viewpoint to such boards without infringing on their autonomy or the agencies or departments they serve.

Language Change

Insert new paragraph under section 204(d).

(7) provide membership on present or future boards or councils created by those departments or agencies listed under Section 203 of this Act.

Title III

Title III authorizes grants to State Agencies on Aging for developing a comprehensive and coordinated delivery system of supportive social services, nutrition services, and multipurpose senior centers. The Title III organizational structure is intended to form a "network on aging" linking the AoA, State and Area Agencies on Aging, other public and private agencies, and local service providers. This network is intended to provide the focal point for a continuum of community services as well as social and economic opportunities for older persons.

Research and program experience have provided a much more diverse picture of older persons than the stereotype of dependency and helplessness that has prevailed in the past. Most older persons are healthy, active, and involved with family and community. Presuming that these individuals are no longer capable of functioning in society when they reach age 60 or 65 denies their humanity and denies society an immeasurable pool of capabilities and human resources. For these individuals with widely varied interests and concerns, opportunities are needed to allow and encourage participation in the mainstream of community life. During this period emphasis should be placed on education and implementation of preventive measures which will retard and delay need for intensive dependent care.

While the majority of older persons function adequately on a day-to-day basis, there are individuals who have become frail and therefore vulnerable to the stresses and demands of daily living. The various elements which contribute to this vulnerability differ widely from individual to individual and from one geographic area to another. For these diverse reasons, the responsibility to define their needs should remain as close to the individuals as possible.
Underlying the diversity of older persons and their circumstances, certain factors have been identified as indicating possible vulnerability—income, race, education, health, and sex. Recent research indicated that other factors, such as living alone or the general mortality rate in the geographic area, may also reflect vulnerability. Age, however, does not significantly correlate with vulnerability or frailty. The wide diversity among older persons and the great range in their needs calls for an approach to service provision that allows for maximum flexibility and provides responsiveness to individual circumstances.

It is virtually impossible for Federal legislation and regulation to be sufficiently specific to efficiently target resources and, concurrently, be adequately responsive to the needs of individuals in various communities. However, national priorities can be set which local entities may then address within the context of community needs and resources. The 1978 amendments to the Older Americans Act began identifying these national priorities by giving preference in the provision of services under Title III to those "with the greatest economic or social need." The 1984 amendments began the process for more flexibility in the use of Title III funds by allowing much more discretion for appropriately responding to the individual needs within the community.

EXHIBITING FOR PROFIT ORGANIZATIONS

8. POLICY

The Council feels that in all parts and titles of the Older Americans Act for profit organizations should be included in the language where their participation may be a possibility.

Language Change

Sec. 301(a) add nonprofit and for profit organizations...

Sec. 302(1)(A) replace private with for profit or nonprofit agency or organizations.

Sec. 302(2) replace private with for profit or nonprofit agency.

AUTHORIZATION OF APPROPRIATIONS

9. POLICY

The Council feels that because current demographics portend a steady increase in the numbers of senior Americans and that Older Americans Act programs greatly benefit the socially and economically needy members of this age cohort, the current annual increment rate of funding should continue during the proposed five year reauthorization period. The Council recommends appropriation figures in Sec. 303 to reflect an annual incremental rate of at least 5 percent.

TARGETING

10. POLICY

The Council feels that some new language is needed to provide for better targeting of the vulnerable elderly and more flexibility for the Administration on Aging and State and Area Agencies on Aging to deal with targeting services to the vulnerable elderly by amending the Act as follows:

Language Change

Insert the following underlined language in Sec. 305(a)(2)(A) and Sec. 306(a)(5)(A):

"provide assurances that preference will be given to providing services to older individuals with the greatest economic or social needs, with particular attention to low-income minority individuals, females, rural residents, those living alone, and functionally impaired, of carrying out the preference."
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Insert at the end of paragraph (1), Sec. 306(b) the following underlined language:

"(1) Each State, in approving area agency plans under this section, shall waive the requirement described in clause (2) of subsection (a) for any category of services described in such clause if the Area Agency on Aging demonstrates to the State agency that services being furnished for such category in the area are sufficient to meet the need for such services in such area or may waive the requirement if the AAA demonstrates that "the ...".

Flexibility

11. POLICY

The Council feels that State and Area Agencies have matured to the point where maximum flexibility in the transfer of funds between parts B and C should be a part of the Act.

Language Change

Repeal paragraphs (4) and (5) of Sec. 308(b), and substitute therefor a new paragraph (4) to read as follows:

"(4) Notwithstanding any other provision of this title, with respect to funds received under section 303[ff]... or for "...", a State may elect in its plan under section 306[ff]... to transfer a portion or all of the funds appropriated for part C between subpart 2 and 3 of part C. or for "...", and may elect to transfer funds appropriated for "..." or "...", or "...", or "...", or "...", or "...", or "...", or "...", and may elect to transfer funds appropriated for "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or "...", or 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Flexibility

12. POLICY

The Council feels that any increase in Federal dollars is limited, therefore, it is necessary to facilitate the brokering role of Area Agencies on Aging, to assure that they, as community focal points in their respective communities, have the primary role in coordination of all community and family resources, and stimulation of the supplementary sources of funding and services, by amending the Act as follows:

Language Change

Add the following subparagraph to Sec. 306(a)(6):

"(L) serve as a broker in activating and coordinating all existing and potential public, (emphasizing the local offices of those agencies enumerated in section 203(b)), private, community, and family resources to solve the problems of and take advantage of opportunities of the area's older individuals, by stimulating supplementary sources of funding and services for them with technical assistance from State agency."

13. POLICY

The Council has met with representative Native Americans tribal organizations and received extensive testimony on the needs of native American elders - evidence calls for relaxing restrictions on Title III services for Native Americans who are served by tribal organizations that apply for Title VI funds, by amending paragraph (3), Sec. 602(a) to read as follows:

"(3) individuals to be served by the tribal organization will not receive for the year for which application under this title is made, services under Title III, unless the application is unsuccessful or a Title VI service..."
14. **POLICY**
The Council welcomed the start made in the 1984 OAA amendments in referencing the demographics of aging in America - 1987 reauthorization language should accent most current demography, by amending the Act as follows:

**Language Change**

Repeal paragraph (2) of Sec. 304(a), which requires that each State be allotted as much under Title III as it received for fiscal year 1984.

15. **POLICY**
The Council feels that because added responsibilities were put on Area Agencies on Aging in past OAA Reauthorization and because the 1987 reauthorization will continue this trend, it is reasonable to increase the administrative cost of these local agencies.

**Language Change**

Section 304(d)(1)(A) such amount as the State agency determines but not more than 12.0 percent, therefore, shall be available for paying such percentage as the agency determines, but not more than 75 percent of the cost of administration of area plans.

16. **POLICY**
The Council is pleased with the active role presently being played by State Long-Term Care Ombudsmen. The Council recommends updating ombudsman language by amending the Act as follows:

**Language Change**

Amend subparagraph (B) of Sec. 304(d)(1) by adding the language underlined below:

"(B) such amount as the State agency determines to be adequate for conducting an effective ombudsman program under section 307(a)(12) shall be available for paying such percentage as the agency determines, but not more than 75 percent of the cost of administration of area plans."

17. **POLICY**
The Council understands that serious discussion is taking place to create a new Section 30 in Title III which would deal with ombudsman services and duties. The Council supports this initiative, however, feels that it added, such a section should include a statement standardizing qualifications, duties, and funding of the State Ombudsman Program.

18. **POLICY**
The Council feels that with the private sector playing an ever larger role in providing services, funds and volunteers to this country's seniors, in order to recognize intergenerational dependency and direct that educational and community efforts reinforce the bonding of the generations, the Act should:

Add to paragraph (6) of Sec. 306(a) a new subparagraph (L), as follows:

"(L) promote educational and community efforts to reinforce the natural affinity and bonding between each community's older individuals and its children, youth and young adults."

Inserting into Sec. 321(a) a new paragraph (19)—and changing the designation of the present paragraph (19) to paragraph (20)—as follows:

"(19) services to reinforce the bonding of generations: or"
19. POLICY

The Council feels to define the word "adequate" as the Congress has used it in the Older Americans Act will help to clarify and bring meaning and effect to the word "adequate" as used in paragraph (2) of Sec. 306(a), which paragraph requires that an adequate proportion of supportive services funds allotted to a planning and service area be used for named priority services. By:

Adding to Sec. 306 a new subsection (d), as follows:

"(d) (1) Each State, in approving area agency plans under this section, shall determine whether such plans provide for spending an adequate proportion of funds as required by paragraph (2) of subsection (a).

"(2) In determining adequacy for purposes of paragraph (2) of subsection (a), each State shall take into consideration the need for that type of service in planning and service areas and the need for using such funds for other services of greater benefit to the area's older individuals with the greatest economic or social needs.

"(3) In the absence of abuse of discretion, as determined by the Commissioner, subject to judicial review, the State's determination under paragraph (1) shall be final."

20. POLICY

The Council has learned in certain jurisdictional affiliations the AAA director has been assigned duties other than those dealing with the Older Americans Act. Because of the importance of continuity in the administration of OAA programs the Council feels it is necessary to require the following language change:

Redesignate paragraph (6) of Sec. 306(a) as paragraph (7), and insert between paragraph (5) and the redesignated paragraph (7) a new paragraph (6), as follows:

"(6) require that the director or other principal employee of the Area Agency on Aging be a full-time employee, devoting all his or her time and efforts as such employee exclusively to the work of the Area Agency on Aging."

TITLE IV

Title IV provides the authority to AOA to support efforts in training, education, research, demonstration, and evaluation which add knowledge to improve program effectiveness and efficiency. The major activities undertaken in each of the Title IV program areas are designed to develop and disseminate information to assist decisionmakers and service providers in addressing issues concerning older persons.

Understanding the processes of aging and the changes to be expected in an aging society are essential in the development of efficient and effective services for older persons. The research, training, and education projects required to attain this understanding are designed and implemented through the policies and practices in business and industry, as well as the various colleges and universities engaged in the study of aging.

21. POLICY

The Council recommends strengthening language in order to emphasize the importance of research, training, education projects and demonstrations in both the academic and private business sectors. In addition, funding levels should be maintained commensurate with past appropriations, with specific allocations to all States, and sufficient to fulfill the charge of Title IV.

There should be a continuing effort to analyze, coordinate, and disseminate findings from completed and future research and evaluation projects in order to better utilize these findings.

Language Change

Amending Secs. 421, 422, and 423, to assure that Title IV grants, contracts, and cooperative agreements can be made under those sections to or with for-profit organizations on the same
basis as they are made to or with public and private non-profit organizations.

Example: Amend Sec. 421(a) by striking language indicated like this:

"SEC. 421. (a) The Commissioner may make grants to any public or non-profit organization and may enter into contracts with any agency, organization, institution, or individual to support research and development related to the purposes of this Act. evaluation of the results of such research and development activities. . . ."

**TITLE V**

Title V, Community Service Employment for Older Americans, mandates the creation of "useful part-time opportunities in community service activities" targeted to those "unemployed low-income persons who are fifty-five years of age or older and who have poor employment prospects." These programs differ from other Older Americans Act (OAA) programs in two significant ways. Title V programs are the only OAA programs to include a means-tested eligibility determination, and the administration of these programs falls under the auspices of the Department of Labor (DOL) rather than the Administration on Aging (AoA). Although various Title V programs differ with regard to the characteristics of participants, types of job placements, and geographic setting (rural or urban), each project shares the same basic goals of providing income and employment, offering training and opportunities for unsubsidized employment, and supplying public services to the community.

Currently, funding for the Title V programs is disbursed among eight national organizations (National Center on Black Aged, National Urban League, Asociacion Nacional Pro Personas Mayores, National Council on the Aging, American Association of Retired Persons, National Council of Senior Citizens, U.S. Forest Service, and Green Thumb-National Farmers Union) and the governors of the various States and territories.

22. POLICY

The Council recommends no changes in this Title.

**TITLE VI**

23. POLICY

The Council recommends one change in Title VI because the recommended addition of Title III as well as Title VI services to Native Americans appears to be the best way to broaden services to this segment of America's elderly cohort.

This decision was reached after numerous meetings between FCA and tribal elders and studying written testimony all of which indicates that tribal elders need the benefits of both Title III and Title VI programs.

The proposed FCA changes in OAA language will require careful cooperation between AoA, AAAs and tribal councils representatives in the writing of regulations implementing such changes should they become law in 1987.

Language Change

Relax restrictions on Title III services for Native Americans who are served by tribal organizations that apply for Title VI funds, by amending paragraph (3), Sec. 602(a) to read as follows: (language to be added is underlined). Additional, recommendations for services to Native Americans are referenced under the Title III section in this document.

"(3) individuals to be served by the tribal organization will not receive for the year for which application under this title is made, services under Title III, unless the application is unsuccessful or a Title VI service..."
24. **POLICY**

The Council supports the thrust of the new Title VII. However, it has come to the Council's attention that in carrying out programs mandated under this Title, States and Area Agencies have been forced to use Title III funds. Council suggests that Congress appropriate funds as authorized for this Title or increase Title III funds accordingly.

**MEMBERS OF THE FEDERAL COUNCIL ON THE AGING**

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Nelda L. Barton, President and Chairman of the Board, Health Systems Inc., Corbin, KY.

Oscar P. Bobbitt, Executive Director, Texas Department on Aging, Austin, TX.

Edna Bogosian, Principal Insurance Examiner, Division of Banking & Insurance, Commonwealth of Massachusetts, Boston, MA.

James N. Broder, Esquire, Curtis, Thaxter, Stevens, Broder & Micoleau, Portland, ME.

Kathryn Dusenberry, Business Executive and Former Member of Pima County Board of Supervisors, Tucson, AZ.

D. Antonio Guglielmo, Owner & Manager, Penny-Henley and Howley Insurance Company, Stafford Springs, CT.

Jon B. Hunter, Director, Region VI Area Agency on Aging, Fairmont, W. VA.

Frances S. "Peg" Lamont, State Senator, Aberdeen, S.D.

Tessa Macaulay, Consumer Affairs, Florida Power & Light Company, Miami, FL.

Mary E. Majors, Private Citizen and Volunteer Programs, Cedar Falls, Iowa

Russell C. Mills, Ph.D., Long Term Care Gerontology Center, Mission Hills, KS.

Josephine K. Oblinger, Director of Senior Involvement, in the Office of Governor James R. Thompson, Springfield, IL.

Edna "Bonny" Russell, Ed.D., Retired Director, Education & Training, San Jose State University, Atherton, CA.

Albert Lee Smith, Jr., Former U.S. Congressman, and Positive Maturity-Retired Senior Volunteer Program, Birmingham, AL.

**REAUTHORIZATION COMMITTEE**

Kathryn Dusenberry, Chairperson

Jon B. Hunter

Ingrid C. Azvedo, Ex-Officio
Senator John Melcher
Attn: Dianne Porter
Senate Aging Committee
620 Hart
Washington, DC 20510

Dear Senator Melcher:

I would like the following information to become part of the hearing record for April 27, 1987 on the reauthorization of the Older Americans Act. I have purposely made my written testimony short, and have included a number of attachments which I hope will interest your staff, and which you may want to include for the record.

My name is Dr. Thomas Rose. I am a Research Associate at The National Center on Aging and Disabilities, Center on Aging, University of Maryland, College Park, Maryland 20742. For the past two years we have concentrated our efforts on understanding and planning for the needs of elderly persons with developmental disabilities and mental retardation.

With my associates we have written a number of articles about Older Developmentally Disabled Adults. We have been especially concerned with the plight of this underserved vulnerable minority. You will find useful statistics and other information in the attached article, and in an article that I have written for the Spring 1987 issue of Aging published by the Administration on Aging. In addition, with my associates, we have presented papers about older developmentally disabled citizens at a number of national and state conferences including: The Gerontological Society of America, The Orthopsychiatric Society, The Association for Gerontology in Higher Education, The Young Adult Institute, etc.

With funding from the Maryland State Planning Council on Developmental Disabilities, we have just completed an 18 month research and planning study about aging and developmental disabilities in Maryland. We have placed emphasis on the policy and programmatic implications as developmentally disabled citizens grow older. Our final report will be available in late April, 1987.

As part of the Maryland study, The National Center on Aging and Disabilities at the Center on Aging has established a National Aging and Developmental Disabilities Information Exchange which offers information on demonstration and model projects, bibliographies, and other materials. I have attached some of these materials with this testimony.

COUGFCE PARK CAMPUS
Room 1120, Francis Scott Key Hall
College Park, Maryland 20742-7321 (301) 454-5556
With the support of a number of foundations and organizations we have organized a national conference on Aging and Life Long Disabilities: Partnership for the Twenty First Century in June, 1987 at the Wingpread Conference Center in Racine, Wisconsin. The participants will include state directors of aging and state directors of developmental disabilities/mental retardation, and representatives of a number of national aging and disability organizations. The cosponsors of this conference include, among others: The National Association of State Units on Aging, The National Association of State Mental Retardation Program Directors, The Joseph P. Kennedy Foundation, and the National Institute on Aging. The final report of this conference will be practical and policy oriented, and distributed to more than 1000 organizations and individuals in the fields of aging and developmental disabilities. I have attached an agenda and summary about the conference.

Finally, the Center on Aging has focused on education and training as more aging developmentally disabled persons are served by the aging and developmental disabilities networks. We have developed a state-wide conference, curriculum materials, two day workshops, bibliographies and resource materials, and have submitted a major training proposal to the Department of Health and Human Services.

If there is any way we can assist your committee, please call on us at anytime. Thank you for making this testimony part of the record.

Sincerely,

Thomas Rose, Ph.D.
Research Associate
Older Developmentally Disabled Adults:  
A forgotten Population  
Part I  
by Dr. Thomas Rose and Dr. Matthew P. Janisidi

Editor's Note: It is timely to focus on a segment of this nation's older population with mental retardation or other forms of developmental disabilities. Meeting the needs of this segment of the population becomes a national concern for the following reasons. There is evidence that this population is steadily increasing, while at state and national levels, there is no cohesive public policy that addresses the increased demand for services. Secondly, this group appears to make up a disproportionate share of institutionalized older adults. Finally, financing available for services to older developmentally disabled adults need to be allocated at increased levels as many of these older individuals are now leaving work-oriented programs due to retraining.

In the October 1986 issue of ANN, the authors, in Part I, will provide an overview of national initiatives and state interagency activities in the development and operation of programs for the older developmentally disabled adult. They identify barriers to service provision and suggest ways in which the developmental disabilities service delivery system could forge a partnership with the aging network.

Mental Retardation and Other Developmental Disabilities

Mental retardation is a severe general intellectual functioning along with deficits in adaptive behavior that occur before age 18 and are carried over into adulthood. There is a great deal of variability in behavior among different individuals who have similar IQ levels related to their individual development. It is estimated that about 87 percent of those individuals with mental retardation are mildly retarded.

Mental retardation is the most prevalent developmental disability. Other developmental disabilities include severe forms of such childhood conditions as autism, cerebral palsy, epilepsy, and a range of neurological or sensory impairments (such as spinal bifida, neurofibromatosis, severe learning disability, and deafness and blindness). However, because someone has one of these conditions, it may not automatically mean that they are mentally retarded or developmentally disabled. In many instances, the conditions alone are not severe enough to affect normal development and cause the individual to be handicapped. They may have been maintained until after childhood when growth and development has already occurred.

An older adult with developmental disabilities is one whose life-long impairment has been carried over into old age. The impairment could be minimal or could continue to pose a barrier to independent functioning. In many instances, old age will compound the problem so that the individual will experience. As a result, it will serve as an "equalizer" when the effects of old age on other older persons is considered.

Older adults with mental retardation or a developmental disability are in many respects like anyone else affected by aging. They need adequate and appropriate housing, activities to occupy their day, a range of support services, and available and accessible health care, transportation, and nutritional assistance.

When older mentally retarded and developmentally disabled adults are severely handicapped, they must likely receive needed services from the network of developmental disabilities service agencies or providers. However, for the majority who are less impaired, there is a growing belief that they should be part of the same service network that provides programs for other older adults. This means being able to access the range of services available or coordinated through the aging network.

Growing Older and Having a Developmental Disability

Many people in the field of developmental disabilities make a distinction between "aging" developmentally disabled persons, that is, those individuals within the greater developmentally disabled population who are 45 to 64 years of age, and "elderly" developmentally disabled persons, those individuals who are age 65 or older.

Many contend that mentally retarded persons are subject to premature aging. Although this may be the case, it is not known whether this phenomenon is due to the effects of certain birth conditions or to genetic factors associated with certain forms of retardation. Individuals with Down syndrome, a major cause of mental retardation, do age prematurely. Many of these individuals appear older by the time they are in their forties and a significant number of them develop Alzheimer's disease.

Dr. Henry Winstead, Director of Developmental Disabilities, and other research scientists are now investigating the link between Down syndrome and Alzheimer's disease. A predisposition to early aging among
adult in other instances, it may be the result of local concerns facing local aging agencies or by their reluctance to serve band-aided persons. The challenge ahead is for policy makers to develop a cohort of older dev-elopmentally disabled persons who can reside with parents, relatives, or foster parents. Two generation senior citizen families are not uncommon in these situations. The parents or foster care provider are often times in their seventies or eighties and are becoming progressively less able to care for their aging developmentally disabled child. Therefore, it is important to address the problem encountered by these families. New community-based residential programs will have to be developed at the local level. As Americans live longer, so will the segment of the population that has developmental disabilities. Some 80 percent of mentally retarded or otherwise developmentally disabled persons will eventually require some type of sheltered living arrangement. Other services such as retirement planning, senior centers, and day care can be institutional in providing assistance in nutrition, health care, and recreation for the older disabled adult. The growth of the older mentally retarded and developmentally disabled population is a reality that must be recognized by policy makers. The problems encountered by these older adults in acquiring and obtaining the information needed to address these situations are of unique and new demand. An information exchange on aging and developmental disabilities issues is available by contacting Dr. Thomas Rose and Dr. Matthew P. Janke of the Center on Aging, University of Maryland, College Park, MD 20742. Dr. Rose, Ph.D. is Co-Director of the Aging and Disability Program at Montgomery County, Rockville, MD. He is also Co-Director of the Aging and Developmental Disabilities Research and Planning Project at the Center for Aging at the University of Maryland in College Park, MD. Matthew P. Janke, Ph.D. is currently a Joseph P. Kennedy, Jr. Foundation Public Policy Fellow at the National Institute on Aging, Bethesda, MD. He also serves as Dr. Rose. As research at the New York State Office of Mental Retardation and Developmental Disabilities...
Older Developmentally Disabled Adults: A Call for Partnership

The federal administrations on Developmental Disabilities and Aging provided the funding for a number of demonstration projects implemented in different parts of the country. The Greater Los Angeles Regional Center for the Developmentally Disabled received funding to plan and initiate services to older developmentally disabled persons through case management services and the planning to integrate them in the local communities.

The private sector also has been active in funding model projects. The Joseph P. Kennedy Jr. Foundation, known for leadership and activities in the area of aging and mental retardation, has funded several demonstration programs. In one project at the University of Alabama in Ohio, Senior Friends serve as companions to older developmentally disabled persons needing aid in obtaining appropriate services in the local aging network. In another demonstration project, the Tri-Valley Elders Services in Southbridge, Massachusetts has funded a number of family care homes. Finally, at the Suicide Shelters Center in Wilton, Massachusetts, professionals and volunteers are trained in generic assessment and clinical consultation techniques taking into account the special needs of the older developmentally disabled adult.

National associations have become aware of the problems of the developmentally disabled adult and have taken a lead in the dissemination of information. Both the American Association on Mental Deficiency and the Gerontological Society of America have established special membership sections to address the special needs of this sub-group of older Americans.

Both of these professional societies have recognized the importance to provide a forum for the exchange of research outcomes and program practices between professionals with a dual interest in gerontology and developmental disabilities. And the membership of the National Association of State Units on Aging and the...
The special needs of the older developmentally disabled adult are being identified by and through national forums. Beth Ram- nome of the National Institute on Adult Day Care recently surveyed a variety of adult day care programs to determine the extent of program participation of the older developmentally disabled adult.

The National Association of Developmental Disabilities Councils has identified the state developmental disabilities councils to give special consideration to the needs of the older developmentally disabled adult in their planning for the future. The 1960 National Training Conference of the National Association of Counties also called on the National Association of Area Agencies on Aging to hold a major presentation on programs for older developmentally disabled adults.

Also, in June 1987, a national conference directed to state directors of aging and developmentally disabled agencies was held at the Winspread Conference Center in Wharton, Texas. According to Dr. Edward Amato, of the University of Maryland, Aging, one of the sponsors of the conference, the program will provide a forum for the nation's public policy leaders to examine the state of the art program, funding mechanisms, cooperative interagency agreements, and model programs in long-term care, day services, and family support to prevent institutionalization.

In order to make more literature available, a national clearinghouse on aging and developmental disabilities in the Aging and Developmental Disabilities Information Exchange was established in 1986 at the Center on Aging at the University of Maryland at College Park. This clearinghouse is a computer-based bulletin board operated by the American Association of University Affiliates of Developmental Disabilities located in Silver Spring, Maryland. The clearinghouse offers information on demonstration and model projects, calendar dates for conferences and meetings held nationwide, and bibliographic materials.

In addition to the information available at the Aging and Developmental Disabilities Information Exchange, a number of new publications have been released. Among these is a special issue of the National Directory of Programs Services: A Manual developed by the American Association of University Affiliates of Developmental Disabilities workers. This manual, entitled "Aging and Developmental Disabilities in the American Community," has been developed to assist programs in the field.

The Ohio Developmental Disabilities Planning Council has provided funding to Dr. Ruth Roberts of the University of Akron to focus on cross training of social workers and developmentally disabled workers. Dr. Roberts has developed an Aging and Disability Training Program, Appendix VIII: Community College located in Rockville, Maryland. There is a need for professional development programs to become more active in integrating gerontology and disability curricula.

The federal government is becoming interested in this type of program. Congress is currently considering legislation that would authorize the Commissioner of the Administration on Developmental Disabilities to establish special university affiliated programs specializing in developmental disabilities to older training in gerontology.

Even though there is increased awareness as to the needs of the developmentally disabled adult, barriers to services do exist in many instances, community-based long-term residential care (in the form of family care and small group home arrangements) is provided by the state through its developmental services delivery network. Likewise, in some instances day activities and other aging services are available from services funded under the aging network. However, there are problems in accessing services in the traditional aging network.

The Needs of the Older Mentally Retarded and Developmentally Disabled Person Can Be Met by Modifying Existing Program Models and Increasing Access to Programs and Services...

There have been many instances where disabled individuals have been denied services by local aging agencies even though they were not entitled to such services due to their eligibility under the Older Americans Act. The barriers that have been set in place are often times insurmountable without extraordinary efforts. Why are barriers present in the delivery of care in the developmentally disabled older adult? In many instances, it is due to "landmarks."

Some aging agencies administrators and participants in programs for the older adult do not want a disabled person in their service programs. However, attitudes based on the inability to handle the disabled individual or to provide the necessary attention, may be overcome through methods that have been designed to change negative attitudes.

In other instances, barriers are cultural in nature. Limited numbers are allocated to area agencies on aging and priorities are often set to preclude setting up services for the elderly disabled adult. With the threat of substantial federal cuts in the Older Americans Act as a result of the passage of Gramm-Rudman, it will be difficult to open up new services and programs for the developmentally disabled adult in the aging network. In order to utilize limited resources, the aging and the developmental disabilities networks should develop collaborative planning and deliver of services.

It must be noted that in many areas of the nation, states do allocate money to pay for services to developmentally disabled older adults. These funds, appropriated to the developmental disabilities state agencies could be used to reimburse for services provided by aging network agencies.

The insulation and fear of the service provider on the aging network may create a barrier. The service provider may not feel knowledgeable or comfortable in providing care to an individual who is mentally retarded or developmentally disabled. What would they do if the patient had a seizure or began to act "strange"? One strategy to reduce the insulation fear and fear felt by the service provider is to provide staff training and assistance in the interaction between the aging and disabled adult network.

Team A Partnership

The needs of the older mentally retarded and developmentally disabled are being met under existing program models used in the developmental disabilities system and increasing access to programs and services provided through the Older Americans Act. In many instances, developmentally disabled service providers can begin to model existing program practices in other areas on activities that are designed to minimize loss of function rather than to eventually permit new learning. Programs can also be redesigned to permit more free time when necessary to permit the older developmentally disabled adult to rent and enjoy some quiet time. Let them take naps, do some time to develop new interests and friendships with other older adults.

Furthermore, many community-based program models in long-term care have proven effective in the developmental disabilities system. For instance, family care and group home are excellent examples of ways in which to reduce institutionalization for both developmentally disabled adults and the older adult.
ent level of detail. Many current provisions of the Act could provide the mechanisms for such service provision.

Lack of understanding about the Older Americans Act of the developmentally disabled population and a lack of knowledge about mental retardation reduce the coordination of the two delivery systems.

The exponential growth of the older mentally, retarded and developmentally disabled population is a fact. Currently, four out of every one thousand people over age sixty are developmentally disabled. The problems faced by these older individuals in accessing needed services must be addressed in a humane fashion. Effective delivery of a wide range of services which include day programming, residential, and health and social services can be accomplished by melding the two specialized delivery systems. It would be a mutually benefi-
AGING AND DEVELOPMENTAL DISABILITIES INFORMATION EXCHANGE

Dear Colleague,

We have developed a national Aging and Developmental Disabilities Information Exchange. We can provide you with:

1. A Bibliography of Publications - Articles and Books
2. A Listing of Conferences and Meetings
3. A Listing of Demonstration and Model Projects
4. A Listing of Other Sources of Information about Aging and Developmental Disabilities
5. Consultants available
6. Audio and Videocassettes available

With the cooperation of the American Association of University Affiliated Programs for Persons with Developmental Disabilities, most of this information may be accessed by members of SCAN (Shared Communication and Assistance Network) on its Electronic Bulletin Board (Address: VZT.WORK). Members of SCAN may send messages to our E-MAIL BOX (Address: Aging.Proj).

We would appreciate any and all information you have on special projects or demonstration programs, special services, interagency agreements, curricula, conferences and meetings, research projects, and special arrangements related to the subject. Anything you send to our Scan E-Mail address or to the Center on Aging will be integrated into our information system.

Sincerely,

Thomas Rose, Ph. D.

Matthew P. Janik, Ph. D.
Co-Ordinators
Dear Mr. Obey,

At the request of John O’Neill, Executive Director of Somerville-Cambridge Elder Services, I am forwarding to you background information on the unique system for coordinating long term care services that exists in Massachusetts.

The Commonwealth of Massachusetts has appropriated $114 million in fiscal 1987 to implement its home care program for the elderly. This home care system, which currently is serving an average of more than 45,000 senior citizens each month, is unique in its structure and range of supportive services. For example:

1. The home care system is implemented through contracts with 27 non-profit corporations throughout the state.
2. Each of these corporations is elderly-controlled. 51% of the governing body of a home care corporation, by statute, must be people over the age of 60. 51% must also be representatives of municipal Councils on Aging. Thus the system is strongly-rooted in the local communities it serves, and is, in fact, controlled locally.
3. The home care system is financially disinterested, i.e. have no financial interest in any of the service providers with whom it contracts. The agencies can advocate for the best service plan for their elderly clients, and make impartial referrals without any financial conflicts of interest.
4. The system is case-managed. Each elder is helped by a home care casemanager. There are nearly 700 such workers in the Massachusetts home care system. These casemanagers assess and authorize the supportive services offered through the home care system.
5. The home care system offers a range of services, from homemaker, chore, and home-delivered meals, to personal care and some limited home health services. A mixture of social and health services are now available through the home care casemanager.

I mention these points because I think they are germane to the issue of how to rationally organize long term care services for the elderly. Our experience since 1973 with the home care delivery model has informed us in many ways about what kind of a system we don’t want for long term care. The features above are positive aspects of our system, but we also know what we want to avoid in Massachusetts:

"independence and dignity for elders"
long term care services should not become "medicalized", i.e.
one dominated by a medical, physician-driven model, because LTC services are, to a great extent, a collection of practical,
family-like, non-technical services.

LTC coordinating agencies should have strong governing ties to
the communities they serve; they should not be directed from
distant corporate board rooms.

coordinating LTC services does not require a new administrative
bureaucracy. In Massachusetts, all the pieces are in place, the
players just need to be coordinated.

Last May, we articulated a series of 13 principles of long term care. I
have attached a copy of these principles as a vision of how we would like
to see community care develop in our state, and beyond.

From these principles of long term care, we developed the rough blueprint
of what we have called the GATEKEEPER model, which builds on the state’s
home care system, and the fact that twenty of the Massachusetts home care
agencies are also Area Agencies on Aging.

Our GATEKEEPER model relies on locally-controlled, non-profit, financially
neutral, assessing and authorizing agencies, which stand apart from the
direct service providers. The objective of GATEKEEPER is to coordinate
health and social services, a goal that will be more attainable when the
blending of funding streams (Medicare, Medicaid, home care, etc.) is
achieved on the national level.

GATEKEEPER relies on a single entry point, one-stop shopping approach to
community care. It would use a single assessment tool for both institutional
and community care, and coordinate the social and health sides of services
by making "per assessment" contracts with health agencies. Such a system
does not require major reorganization or consolidation of service providers.
The home care GATEKEEPER model channels care more effectively, but does not
force home health agencies to merge with larger entities or lose market
share because a gatekeeper exists.

GATEKEEPER is a practical blueprint towards better coordinated care. The
model can become more sophisticated once the federal government improves
financing coordination. Unlike most models we have seen discussed on the
federal level, GATEKEEPER maintains strong consumer control over the LTC
system, and does not turn custodial care into a medically-dominated system.

Most of all, we think the home care GATEKEEPER model works. We base that on
the fact that our system has successfully worked with hundreds of thousands of
Massachusetts elders over the years. Our system is now providing personal
care and home health care using a case manager model.

We would be pleased at any point to discuss the home care system in the
Commonwealth with the Committee as you proceed with your investigations
on how to organise long term care for the nation’s elderly.

Yours,

Al Norman
Executive Director, Mass Home Care

"independence and dignity for elders"
To: MASS HOME CARE members and Boards of Directors
From: Al Hotham, Exec. Director
Mass Home Care
Re: GATEKEEPER MODEL

Date: 7/28/86

At the July 21st. meeting of the MASS HOME CARE Association, our membership voted to support the attached generic model for coordinating community-based health and social services for elders in need of long term care—the so-called "GATEKEEPER" model.

This model attempts to diagram the principles of long term care that our Association published in May. You will note that this model has as significant features a local long term care agency that:

* is controlled by local senior citizens

* is private, non-profit

* is "financially disinterested", that is, does not profit from direct service delivery, but is able to serve as the impartial advocate for the elderly client because it is not in the business of direct service provision.

* coordinates health and social services by use of "per visit" assessment contracts with home health agencies.

* includes pre-screening for institutional and non-institutional long term care services.

* is responsible for monitoring and evaluating direct service providers.

* uses a single assessment tool to conduct assessments.

"independence and dignity for elders"
GATEKEEPER MODEL

Under this model, the long term care gatekeeper agency would locate, coordinate and monitor direct service providers, but the gatekeeper remains financially neutral, and therefore impartial in its referral patterns. Gatekeeper would be a private, non-profit agency with elderly control of governing body. Model relies on a single assessment tool, and integrates community and institutional intake into one lead agency. Supportive LTC services would be augmented by health services through assessment contracts with home health provider agencies.

- doctor
- hospital
- service agencies
- family
- self institution
- other

Referral Sources

Case-Management Gatekeeper Intake

Joint Assessment
Income Eligibility
Functional Impairment
Need for Service

Caseplan Conference
with client/family

Service Authorization

Institutional Services

Community Health Services

Supportive & Custodial Services

Case Management
Quarterly Caseplan Monitoring

Revised Authorization

Step One: Intake Referrals for health assessment

Step Two: Joint Assessment
Joint Assessment Tool

Step Three: Plan reviewed
with family

Step Four: Authorized

Step Five: Service Delivery

Step Six: Monitoring

Impartial Referral Pattern
Community-Based Long-Term Care in Massachusetts

A Statement of Principles

May, 1986

Prepared for the Special Commission on Elderly Health Care
Community-Based Long-Term Care

Statement of Principles

1. Long-Term Care services, to a great extent, are a collection of practical, family-like, unspecialized, non-technical services, and should not be viewed as predominantly health care. See Channeling data on mix of social-health services: 80% social services, of which 64% was homemaker/personal care.

2. LTC services must be mediated by a case management system which is responsible for locating, coordinating and monitoring a group of services. Each service area should have a gatekeeping agency which oversees case-finding, functional assessment, care planning, service authorization, reassessment, and monitoring (programmatic and fiscal). See the 1983 Senate Ways and Means Policy Report #17 which said “home-care corporations are best suited to manage such a system.”

3. A LTC case management system must meet the following criteria:

* The case management system must be publicly accountable for cost and control over services.

* The case management agency should be as financially disinterested as possible, and separated from service delivery, unless there is no other agency available to provide a given service. (See 651 CMR 3.01(2) state home care regulations—"Except for case management and I&R, a home care corporation may not provide a direct service unless authorized"—and Older Americans Act regulations—1321.103: "An area agency must use subgrants or contracts with service providers to provide all services, unless...direct provision of a service using its own employees is necessary to assure an adequate supply of services.")

* The goal of the case management system should be to supplement family care, not to supplant it.

* The case management agency must have greater control over case-finding and its own intake, including the institutional pre-screening function.
4. LTC services should not be viewed as an extension of medical programs, or as an appendage to the health care system, but as supportive human services addressing functional impairments. "In Massachusetts, a health agency tied to Medicare would not be an appropriate designated agency. While access to medical services is important, experience with case management and social services is vital." (Secretary Rowland 1/31/84 to U.S. Senate Subcommittee on Aging)

5. The LTC system should be consumer-oriented, community-controlled (elders controlling governing bodies), and non-profit. Governing bodies of LTC agencies should include "to the extent feasible, recipients of or having familiarity with" LTC services. (651 CMR 3.01(2).)

6. There should be a single LTC coordinating agency in each service area. Entry points in any given community should be simple to access, treat all who may need services in an equal and consistent manner, and be available throughout the community. The intake system should permit local flexibility, i.e., an intake system could consist of one, or a series of case-manager/nurse screening teams, with the LTC agency providing the health assessment component directly or through contracts with affiliated home health agencies. See the LTC Work Group proposal that "home care corporations would issue RFPs for the selection of home health agencies to participate."

7. LTC entry points must be visible, and well-marketed.

8. The LTC system in Massachusetts should capitalize on the fact that 20 of the 27 home care corporations currently in existence are also designated Area Agencies on Aging, and have, therefore, access to Older Americans Act funding in support of a comprehensive and coordinated system of long-term care services. OAA resources should be more clearly marshalled in support of LTC programs in each service area. OAA funds exist to develop "comprehensive and coordinated systems for the delivery to older persons of supportive services." (45 CFR, Chapter XIII, Subchapter C, Part 1321.1(b).)

9. The LTC case management system in Massachusetts cannot possibly carry out its mandate as listed above given current caseloads of 65 cases per case manager. (Channeling had a
50-to-1 ratio.) Caseloads need to be reduced, and salary levels need to be upgraded beyond the current entry level for a home care case manager.

10. The LTC financing system must become a "pooled" system. LTC agencies could function with an overall cap on expenditures, using capitated per diem rates similar to those developed in the Lynn Channeling project.

11. Massachusetts has a well-developed direct service delivery system, and the LTC case management system need not result in any significant restructuring of the provider network. (See LTC workgroup statement: "Problems of access may not require substantial reorganization of local service arrangements.")

12. The state should provide "development grants" to lead agencies in each service area to put together local LTC models, including funding for system marketing.

13. The LTC system should focus on those elders in Massachusetts who have two or more impairments in activities of daily living, or in basic environmental tasks (instrumental activities of daily living), especially those who are at risk of institutionalization. See 651 CMR 3.03(3)(a)(1) Functional Impairment Levels.

Many of the principles needed to guide a Massachusetts long-term care case management system are currently in place. The existing home care corporation network, as developed in Chapter 19A, is the best suited system to oversee the service area specific work needed to better coordinate entry into the system. The service delivery system has some serious gaps, to be sure, but the provider system is a mature system with a strong track record of experience in serving the needs of Massachusetts senior citizens.
My name is Dick Ladd. I am the Administrator of the Oregon Senior Services Division. I welcome the opportunity to present written testimony on the subject: "The Need for Development of Quality Assurance Standards for In-Home Services." For reasons which I will discuss, I wish to discourage additional regulations and quality assurance standards for in-home services.

The Oregon Senior Services Division has a special interest in the quality and service delivery of in-home services. Social policy, explicit in Oregon statutes, directs the State to promote independence of the State's seniors. Specifically, the statute says that the State will:

2. Assure that older citizens retain the right of free choice in planning and managing their lives; by increasing the number of options in life styles available to older citizens; by aiding older citizens to help themselves; by strengthening the natural support system of family, friends, and neighbors to further self-care and independent living; and by encouraging all programs that seek to maximize self-care and independent living within the mainstream of life.

3. Assure that health and social services be available that:
   a. Allow the older citizen to live independently at home or with others as long as the citizen desires without requiring inappropriate or premature institutionalization.
   b. Protect the older citizen from physical and mental abuse and from fraudulent practices.

Oregon's Long-Term Care program is based on the concept that most older citizens who require long-term care need social services. The long-term care clients need assistance with activities of daily living because of chronic functional impairment. Only a small percentage of long-term care clients need acute medical services or services provided by skilled medical providers.

The services that long-term care clients need include assistance with shopping, meal preparation, and eating; housekeeping and maintenance of the home; supervision related to behavior problems, including reminders and money management; assistance with toileting, dressing and grooming, bathing, and personal hygiene; and assistance with problems related to mobility and transportation. These services can best be provided using a social model, not a medical model. For most long-term care clients these services can be delivered by home care providers.

For clients with additional medical problems, home care services can be supplemented with personal care or home health services.

The majority of Oregon's home care is delivered by independent home care providers who are hired by the client. The program is called the Client Employed Program. We find the program very effective. The model is used when a client can direct his/her own care. Home Care is also provided by agencies when the client is unable to direct his/her own care or is unable to make an appropriate judgment about care, thus requiring that the supervision of the provider come from another person. Both home care programs are social service programs.
The key to assuring the effectiveness of home care services is the assessment and on-going monitoring of the client's impairment level and need for services. Oregon has a statewide casemanagement system and a comprehensive assessment tool. The service need can be accurately determined, planned, implemented, and monitored. Not only is it cost effective for the client to employ his/her own provider and direct his/her own care, but the model promotes independence and interaction between the client, the provider, and the case manager. The effectiveness can be determined by the outcome of the service: the client's needs being met.

We believe that the additional administrative costs of providing the supervision and monitoring of providers to assure that the provider meets quality assurance standards, could price home care service out of the market. More important, however, we find that increased regulation does not improve the outcome of the service.

Oregon has mandatory reporting laws for both Nursing Facility Resident Abuse and Elderly Abuse. Concern has been raised that unregulated home care providers may abuse vulnerable older persons. Oregon's reports indicate that most reported abuse occurs in Nursing Facilities and Adult Foster Homes, two of the highly regulated programs. The abuse reports for 1986 and first three months of 1987 indicate that In-Home complaints represent only 1.5 percent of total complaints of providers of care.

Until more information is available that would indicate a need for increased regulation, Oregon opposes any regulation that promotes dependence, moves home care in the direction of a medical model, or increases unnecessarily the administrative and services costs of delivering In-home services.

<table>
<thead>
<tr>
<th>ABUSE COMPLAINTS</th>
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<td>JANUARY 1986 - MARCH 1987</td>
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<table>
<thead>
<tr>
<th></th>
<th>Number of People</th>
<th>Number of Complaints</th>
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<td>In-Home Care</td>
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<td>0.006</td>
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* Only includes public clients (Nursing Homes and Adult Foster Care include both public and private clients).

NOTE: In-Home Care complaints represent 1.5% of total complaints of providers of care.

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4/23/87
Home Care and the Reauthorization of the Older Americans Act

on behalf of

THE LEGISLATIVE COALITION FOR THERAPEUTIC RECREATION

National Therapeutic Recreation Society
American Therapeutic Recreation Association
National Consortium on Physical Education and Recreation for the Handicapped

Document prepared by
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THERAPEUTIC RECREATION AND HOME HEALTH CARE:
RECOMMENDATIONS FOR AMENDING THE OLDER AMERICANS ACT OF 1965

One of the fastest growing aspects of services to older Americans is home health care. Yet, by many measures these services are unregulated and poorly defined. The wisdom of the Senate Special Committee on Aging is evident in its attempts to study the home care industry, and to consider ways in which the Older Americans Act can serve as a vehicle to expand and ensure the quantity and quality of home care.

The LEGISLATIVE COALITION FOR THERAPEUTIC RECREATION welcomes this opportunity to provide the Senate Special Committee on Aging with background information on therapeutic recreation services which have been used and can be further used to
supplement the home care provided to our Nation's older individuals. This Coalition (see attached) represents professionals dedicated to the use of recreation as a means for rehabilitation, education and community integration and independent living.

**Recreation and the Older Americans Act**

The Older Americans Act of 1965, as amended has a 22-year history of recognizing the importance of recreation and leisure in the lives of older individuals. Title I, Declaration of Objectives, includes among other objectives *the pursuit of meaningful activity within the widest range of civic, cultural, and recreational opportunities* (67), and *freedom, independence, and free exercise of individual initiative in planning and managing their own lives* (81).

Title III, Part B (Sec. 521) authorizes social services to include, among other services, (1) recreational services, and (7) services designed to enable older individuals to attain and maintain physical and mental well-being through programs of *regular physical activity and exercise*. Authorized social services also include reader and letter writing services, health, continuing education and informational services, all of which can be directly related to the recreational and leisure involvement of service recipients, and are intended to contribute to their dignity and independence, and prevent institutionalization.

Finally, Title IV, Part E (Sec. 441) (3) authorizes *multidisciplinary Centers of Gerontology to conduct basic and applied research on the leisure issues pertaining to older adults*. This affirmation of recreation's importance has resulted in extensive recreational programs for our Nation's elderly, especially through senior centers sponsored by local councils on aging. However, with few exceptions, this has not extended into the home care industry.

The Department of Health and Human Services Office of the Inspector General recently completed a study of home health care and home health aides. This study raises serious concerns about the quality of the care provided. Although aides performed most of the personal care services, it was found that they failed to
perform supportive specialized services. This failure seriously compromises the full benefits of home care and prevents the older persons from realizing their fullest rehabilitation potential. The impact of this type of care on the independence, dignity and quality of life of older individuals can only be speculated, but it is clearly not in the desirable direction. Further, one can easily conclude that the recreational needs of these individuals are consistently neglected. Indeed, it is time for the home care industry to be improved, and to be composed of quality services that address needs beyond the most basic personal care of home-centered persons.

The Need for Home Care

The improvement and expansion of home care for the elderly is receiving priority attention for several reasons. First, great value is placed on maintaining independent living and staying off institutionalization as long as possible. This is of value to society in general and consumers in particular. Secondly, the cost of hospital and nursing home care has been escalating. The introduction of the diagnostic related (DRG) groupings, intended to combat soaring costs, has resulted in reduced hospital stays and increased ambulatory care services. The hopeful perception that home care can reduce health care cost contributes to an emphasis on expanded home care utilization.

One of the basic questions posed to the home care industry regards what MIX OF SERVICE should be provided in the continuum of care between the institution and the community. The increasing number and proportion of elderly in the population, an upward trend in life expectancy, the increased likelihood of living alone at older ages, and chronic conditions and health problems affecting activity suggest the need for a variety of support services. Currently, alternatives to institutional care are of paramount importance to providers of these services to older persons. The question of risk of institutional placement, usually in nursing homes, appears to be an interplay of physical condition, mental health, functional health, community and family support, finances and relatively barrier-free environment. Many of these specific problems are treatable and can either be corrected or managed on a continual basis. However, strategies for diminishing the risk of institutional care have largely resembled what might be referred to as "custodial" care.
In-home services can be a more appropriate and cost-effective alternative to institutional care. These services can be directed particularly at those who could be maintained at home if appropriate living arrangements and support systems could be established. As previously stated, present in-home services have focused almost exclusively on needs related to medical and personal care. While these services are important, an obvious lack of emphasis on psychosocial and expressive needs is evident. Rehabilitative home care cannot be conceived solely in maintenance or custodial terms. Efforts must be extended toward providing services conducive to meeting higher order needs, beyond merely, survival.

**Therapeutic Recreation Services**

The purpose of therapeutic recreation is to facilitate functional improvement, well-being and life quality. Quality of life may be defined as an individual's opportunity for responsibility and dignity, choices, relationships, competence, and community presence and participation. Improving the quality of a person's life through a focus on recreation and leisure is more complex than just providing enjoyable activity or delivering segmented therapy utilizing activity as a medium.

Therapeutic recreation refers to the specialized application of recreation for the specific purpose of intervening in some physical, emotional, or social need, and facilitating change, growth and development. Depending on the needs, services can be designed to be treatment-oriented, educational, or advisory (i.e. providing or directing an individual to the necessary resources - either in the home or in the community - for independent recreation and leisure involvement.

A certified therapeutic recreation specialist works with the client, family, and the professional team. However, home health aides, with the proper training and supervision, could provide many aspects of therapeutic recreation services.

Idyl Arbor, a licensed private for-profit health care business in Ravenadale, Washington, is an example of quality home-centered recreation therapy. Certified therapeutic
recreation specialists receive referrals from hospitals and home health agencies with the specific request to assist clients in using recreation to mitigate illness, prevent regression, and expedite the acquisition of independent functional skills.

Attending to psychosocial needs, recreation and leisure activities are used to stimulate initiative, motivation and compliance in matters related to self care, nutrition, exercise and social involvement. Transportation skills, cognitive skills (such as orientation, following directions, using memory, and decision making), social skills, and the use of community resources such as the senior centers, are all within the framework of recreation therapy. The services offered through Idyll Arbor, and other programs similarly designed (see Wilhite, 1987) appear to influence the avoidance of institutionalization and the need for further, perhaps unexpected, medical care. Such programs and services can: a) contribute to independent functioning, b) increase compliance with prescribed physical exercise routines, and c) positively influence motivation and feelings of dignity and self worth.

Recommendations

With the above commentary in mind, the LEGISLATIVE COALITION FOR THERAPEUTIC RECREATION respectfully submits to the Senate (Special Committee on Aging the following recommendations for consideration in the reauthorization of the Older Americans Act of 1965, as amended.

1. Amend Title III, Grants for Programs on Aging, to add a new part devoted exclusively to home care. Services authorized under home care include but are limited to therapeutic recreation services.

   (Regulations would presumably contain specifics about scope of such services, qualified personnel, etc).

2. Amend Title IV...Training, Research and Discretionary Programs, Sec. 411.(a) (1) insert RECREATION after health care
3. Amend Title VII, Older Americans Personal Health Education Training Program as follows:

Sec. 704 (b)(1) insert THERAPEUTIC RECREATION after health education.

Sec. 704 (b)(1)(D) insert RECREATION after physical fitness.

Sec. 704 (b)(1)(F) insert THERAPEUTIC RECREATION after physical fitness.

Sec. 704 (b)(1)(H) insert THERAPEUTIC RECREATION after health education.

Conclusion

The Senate Special Committee on Aging is seeking to respond to the need for quality and appropriateness of home health care, and is to be commended for its leadership in logically looking to the Older Americans Act for a focus for addressing this need. As this Committee has so aptly noted, home care cannot focus exclusively on personal care and homemaker services. Those aspects of an older person's life that give meaning and purpose need to be rigorously examined for their contribution to independence, dignity and well being. Therapeutic recreation services, as an aspect of home care, can help ensure that life is added to the older years, rather than years to the older person's life. The LEGISLATIVE COALITION FOR THERAPEUTIC RECREATION is committed to working with the Congress to ensure that our Nation's older citizens receive quality health care -- whether in the home or away from it.
The purpose of the LEGISLATIVE COALITION FOR THERAPEUTIC RECREATION is to monitor legislative and regulatory matters pertaining to therapeutic recreation and recreation for special populations. The COALITION collaborates with public affairs offices and legislative action committees of its constituent organizations on related public policy and membership education, information and action. The COALITION represents various professional organizations* committed to promoting and protecting the role of recreation in the treatment, education and community living of individuals with illnesses, disabilities, or other handicapping conditions. The COALITION strives to ensure a consolidated and consistent approach to working with Congressional committees and federal agencies on behalf of the interests and concerns of the member organizations and the public it serves.

* The National Therapeutic Recreation Society (NTRS) is the professional branch of the National Recreation and Park Association dedicated to improving and expanding opportunities for individuals with disabilities to experience personal development and fulfillment and functional improvement through recreation and leisure.

The American Therapeutic Recreation Association (ATRA) is a non-profit professional organization committed to advancing the role of therapeutic recreation as an effective and efficient component of rehabilitation, habilitation, education and medical treatment of clients in health care and human service settings.

The National Consortium on Physical Education and Recreation for the Handicapped (NCPERH) consists of professionals in the fields of adapted physical education and therapeutic recreation involved in promoting and stimulating programs and services, and conducting professional training and research and the dissemination of public information related to the physical education and recreation needs of our Nation's 4.3 million handicapped children and youth.
APPENDIX 2—FOLLOW-UP ANSWERS

The Honorable John Melcher
Chairman
Special Committee on Aging
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

Thank you for the opportunity for Charles Wells, Deputy Commissioner on Aging, to appear before the Senate Special Committee on Aging on April 27 to present testimony on the subject of in-home services provided under the Older Americans Act.

The purpose of this letter is to provide responses to six additional questions related to the Older Americans Act which you addressed in your correspondence to Mr. Wells dated May 13, 1987. We have enclosed our responses to each of yours and Senator Heinz’s questions.

I hope that these answers will be helpful to you in the Committee's activities related to reauthorization of the Older Americans Act. A similar letter has been sent to Senator Heinz.

Sincerely,

Ronald F. Decker
Assistant Secretary for Legislation

Enclosure
Question 1: How much of Title III-B funding is dedicated to in-home services such as respite and personal care? How many people are receiving in-home services? How does this break down per individual served?

Answer:

In FY 1986, approximately $259.7 million was allotted to State Agencies on Aging, after transfers, under Title III-B of the Older Americans Act for supportive services. (State Agencies on Aging have the authority to transfer limited amounts of funds among the three Title III allotments in order to better reflect their local needs and priorities). This figure represented 42.8 percent of the $640 million available during FY 1986 under Title III.

The Administration on Aging (AoA) does not require States to report the distribution of funds used specifically for the three types of supportive services provided under Title III-B, i.e., access, in-home and legal assistance services. Title III-B funds are used as the States themselves best see fit for a whole variety of services including in-home services. States do provide, however, estimates of the number of client contacts and the type of supportive services provided under Title III-B. During FY 1986, these in-home services and the estimated number of client contacts were:

| Homemaker services | 736,342 |
| Home health aid services | 148,050 |
| Visiting/Telephone contacts | 998,601 |
| Chore maintenance | 253,981 |
| All other in-home services | 335,388 |
| **Total in-home client contacts:** | **2,473,162** |

The 2.47 million client contacts for in-home services does not represent an unduplicated count of elderly persons receiving such services, since States frequently report clients as receiving more than one type of Title III-B service. Data provided by States do not permit an estimate of the cost of an in-home service per client contact, since clients may receive multiple services under Title III-B.

Question 2: How can you assert that [industry accreditation and the certificate of need program] are the best approaches for assuring quality care?

Answer:

In Mr. Wells' testimony on April 27 before the Special Committee on Aging, he indicated that AoA is very much committed to the provision of quality care in the services that are provided to every older person - and their families - under the Older Americans Act. Through a number of research and demonstration efforts, AoA is continuing to help build a knowledge base that will assist State and Area Agencies on Aging to better assure the quality of home care for older persons.

These efforts include a project with the Ohio Department of Aging to design, implement, and evaluate a model quality assurance program for in-home services for elderly care recipients. A second project, being conducted by the Clackamus County, Oregon Area Agency on Aging is replicating and testing a local/State quality assessment program.

We do recognize, however, that assuring quality for in-home services is a challenging problem involving many complex issues. Quality assurance in services is made difficult for a variety of reasons. The need for home care has increased greatly in recent years. Concurrently, the number and variety of service providers providing such care also have increased. Additionally, the number and types of services needed by elderly persons in the home vary greatly in their complexity and cost. In sum, the home care industry is rapidly growing and changing. It must also be recognized that many home care services are provided not only by professional service organizations but by family members and friends.
Even defining "quality" in home care services is a difficult and complex task, since the concept of "quality" has many dimensions and interpretations -- physical, social, psychological.

In spite of these and other problems related to the issue of quality home care services for older persons, AOA believes that States and local entities, including the private sector, remain the most appropriate locus of setting standards and monitoring the quality of performance by those who provide home care services. In the testimony on April 27, Mr. Wells provided some examples of quality control systems which have been implemented to regulate home care services and to help assure better quality in such services. At the Federal level, the regulation of home care has been primarily Medicare certification for home care agencies, while licensure is the regulatory mechanism most frequently used by States.

Several other important approaches for helping to assure quality home care services have emerged in recent years. One of these is industry accreditation. The National League for Nursing (in conjunction with the American Public Health Association), the National Home Caring Council, and the Joint Commission on Accreditation of Hospitals are three major accrediting organizations that have made important contributions to home care quality services.

While no one approach can be necessarily identified as the best system for assuring quality home services, industry accreditation coupled with existing State licensure, Federal Medicare regulations, and other legal and marketplace controls are, we feel, viable and effective mechanisms for improving the quality of home care services, depending on the needs of individual States, communities, and consumers.

Question 3: Do you think the long-term care ombudsman should have the expanded responsibility, authority, and resources to investigate home care complaints? If so, what resources would be necessary for ombudsmen to be effective in this area?

Answer:

The Administration on Aging believes that it would be inappropriate for the Federal government to mandate that the State long-term care ombudsman's responsibilities be expanded to investigate home care complaints. Even with significantly increased resources, such additional responsibilities would not be feasible in many States.

The long-term care ombudsman program is based on an institutional model in which program specialists and volunteers advocate for persons in institutional settings. Specifically, the role of the ombudsman is to help individual residents and their families negotiate with nursing homes and regulatory agencies. Through their ombudsman programs, States address such issues as nursing home regulations, abuse of residents' personal funds, and restrictions on access to nursing homes. The knowledge, training, and organizational approach that would be necessary for monitoring home care services is different from that currently utilized by the long-term care ombudsman in institutional settings. Whereas the resolution of complaints is the current principal role of the ombudsman, this responsibility would only be one component necessary in monitoring and assuring quality care for in-home services.

The ombudsman program also is highly reliant upon the use of volunteers. Data for the ombudsman program for FY 1986 have been computerized and are currently being summarized. During FY 1985, however, paid full and part-time staff in the ombudsman program totaled about 1,000 persons, while nearly 8,000 volunteers, whose efforts are critical to the success of ombudsman activities, provided services in this program.
Working with individuals, the focus of the ombudsman program is primarily problem-solving in nature, not regulatory. Ombudsmen have legitimate and important roles in consumer protection, and because they are not regulators, they can effectively mediate problems between consumers, service providers, and regulators. In FY 1985, the number of complaints reported to ombudsman programs totaled approximately 83,700 with 77 percent investigated and 62 percent resolved or partially resolved. These numbers represent formidable responsibilities and activities undertaken by ombudsmen. Only in three States—Maine, Virginia, and Wisconsin—do State ombudsman programs have a State mandate to monitor home health care services.

It has been estimated in a recent publication of the Senate Special Committee on Aging, Aging America: Trends and Projections, that approximately 5.2 million persons over age 65 need assistance with personal care. These figures will rapidly increase in the decades ahead. The immense need for services which these figures represent, in addition to the diversity of services needed, would make effective monitoring and investigation of complaints on in-home services by ombudsmen extremely difficult.

States now have the authority to regulate home care services through such mechanisms as licensure. AoA believes that States, in conjunction with private sector and professional organizations, are the most appropriate entities for assuring quality home care services.

Question 44: You stated in your prepared testimony that coordination of home and community based services should be required activity of State and Area Agencies on Aging. How could we make sure that the coordinated services are of sufficient quality? Would you recommend that additional resources be given to the area agencies on aging to oversee these services?

Answer:

The Administration's proposed amendments to the Older Americans Act, recently introduced as S. 1133, would require State plans to assure that area agencies facilitate the coordination of home and community-based services to vulnerable elderly individuals. The bill would define vulnerable elderly individuals as those who have attained 65 years of age and who either: (1) reside at home and are at risk of institutionalization because of limitations on their ability to function independently; (2) are patients in hospitals at risk of prolonged hospitalization, but could be returned to the community if home and community based services were available; or (3) are patients in skilled nursing facilities or intermediate care facilities, but could be returned to the community if home and community based services were available. We believe that the coordination of home and community based services for the vulnerable elderly is important enough that it should be a State plan requirement and a mandated Area Agency activity.

We believe that Area Agencies on Aging, in light of their experience in developing and implementing service programs over the past 22 years, are in a unique position to coordinate and improve the quality of the wide range of health and social services needed by vulnerable elderly persons to remain in the community. It is the position of the Administration on Aging that the administrative funds currently available to Area Agencies on Aging are adequate to carry out their coordination responsibilities.
Question 5: In light of the testimony we heard at the hearing about quality problems, will you recommend to Secretary Howen that the Department support a mandatory aide training program, with a national standardized set of criteria, for aide and homemaker services funded under the Older Americans Act and other programs?

Answer:

We believe that the future of the program under the Act clearly lies with State and Area Agencies on Aging. States themselves have the authority to train home care services providers through State colleges and universities. States also have the authority to establish standards of criteria through their own legislative and regulatory processes. AOA believes that States, therefore, in conjunction with private sector and professional organizations, are the most appropriate entities for training and regulating in the area of home care services.

Question 16: With the reauthorization of the Older Americans Act this year, there has been a great deal of discussion about adding a sliding fee scale to the provision of many OAA services. Do you think that a fee scale will create barriers to serving the elderly who need OAA services the most, i.e., those with low incomes? Isn't a fee scale contrary to the intent of the OAA -- to provide services to all older Americans?

Answer:

The Administration's proposed amendments to the Older Americans Act, recently introduced as S. 1133, would permit States, at their option, to permit Area Agencies to charge fees, based on ability to pay, for supportive services under part B of Title III. The State Agency on Aging would be required to ensure that no fees for such services were charged to low income individuals. It would be left to State discretion to determine which supportive services would be subject to fees. As under current law, there would be no authority to charge fees for nutrition services under part C of Title III.

This amendment would help to ensure the most effective use of limited program funds, as fees collected from those able to pay would enable area agencies to expand services available to those unable to do so. Area Agencies would remain free to seek only voluntary contributions; however, the proposal would complement that authority.

We believe that a fee scale, rather than being contrary to the intent of the Act, is a viable method for targeting resources to those who are least able to pay for them. Further, we believe that this solution is an acceptable alternative to increases in authorization levels during a time when the Congress and the Administration are working toward reducing the Federal deficit.
Dear Mr. Secretary:

As Chairman of the Special Committee on Aging, I am writing to request that you direct the Health Care Financing Administration (HCFA) to take immediate action toward promulgating a regulation mandated by the Congress in 1980. Specifically, I am referring to a provision in the Omnibus Reconciliation Act of 1980, which amended Section 1861(m)(4) of the Social Security Act to require that home health aides "complete a training program approved by the Secretary [of Health and Human Services]." The Committee was deeply disturbed to learn on Monday in a Committee hearing on home health care that the Department has yet to comply with this law, enacted almost seven years ago.

I cannot emphasize too strongly the urgency in the need for a mandatory home health aide training program. Testimony during the Committee hearing included shocking and alarming statements from recipients and providers of home health care concerning caregivers who were incompetent, negligent, and even abusive to their patients. A recently completed report, "Home Health Aide Services For Medicare Patients," by the Department's own Office of Inspector General further confirms the need for adequate standards pertaining to training and supervision of these caregivers. Moreover, a recent study conducted by the National League for Nursing revealed that 44% of home health aides surveyed could not read a thermometer, and 31% did not even know how to take a patient's pulse.

I am at a complete loss to understand HCFA's dereliction in having failed to publish the required training regulation, especially since that agency completed a draft of the regulation some three to four years ago. Even more puzzling was the testimony submitted by Louis B. Hays, HCFA's Associate Administrator For Operations. Mr. Hays acknowledged HCFA's failure in not having established the required regulation, but then went on to state: "We have recently become aware of this situation and have taken steps to publish a proposed regulation..."
as soon as possible." Mr. Hays estimated that the regulation could be published in "a couple of months." I find Mr. Hays' timetable to be unacceptable, in light of the fact that a draft of the regulation was completed several years ago.

Therefore, please let me know as soon as possible when this regulation for home health aide training will be published. In addition, I would like a detailed account of why the Department and HCFA failed during the past seven years to comply with the Congressional mandate concerning the training program for home health aides.

Should you or your staff have any questions regarding this request, please have your staff contact Max Richtman, the Committee Staff Director.

I am sure you appreciate the urgent need for quick action on this statutory requirement, and I look forward to your cooperation and assistance in this important matter.

Sincerely,

[Signature]

John Melcher
Chairman

JM:jfm
The Honorable John Melcher
Chairman, Special Committee on Aging
United States Senate
Washington, D.C. 20510-6400

Dear Mr. Chairman:

This is to acknowledge receipt of your letter of April 29, 1987, urging that immediate action be taken to publish a regulation for home health aide training.

A response will be provided to you as soon as possible.

Thank you for bringing this matter to my attention.

Sincerely,

Otis R. Bowen, M.D.
Secretary
The Honorable John Melcher  
Chairman, Special Committee on Aging  
United States Senate  
Washington, D.C. 20510-6400  

Dear Mr. Chairman:

I am responding to your letter concerning the requirement for training of home health aides. I am sorry that my response has been delayed.

As Mr. Hays indicated at the hearing, which you mentioned, we were quite distressed to discover that regulations had not been issued implementing the statutory requirement for training of home health aides. You asked us for a detailed account of the reasons for the delay in issuing regulations. I believe that the best answer is that regulations on this provision were overlooked because of the numerous additional provisions enacted in subsequent Reconciliation Acts.

Regardless of what has gone before, I am committed to developing and issuing regulations to implement this requirement. Although you suggested that we need only to publish the draft regulations developed several years ago, this is not the case. We have thoroughly reviewed this draft in the light of events that have occurred since it was written, including the Inspector General's report. I have been advised that the Health Care Financing Administration has made some alterations to the draft and are preparing to submit it to the Department for review. Under the established procedures, we believe we will have published the proposed regulation by August. The speed with which a final regulation is published relates in part to the volume and content of the comments we receive on the proposal, and we will establish a schedule for a final regulation once the comment period has closed.

I share your determination to see that this statutory requirement is implemented, but I believe you will appreciate that the action we propose to take must be carefully considered.

Sincerely,

Otis R. Bowen, M.D.  
Secretary
INVESTIGATION OF HOME CARE PATIENT COMPLAINTS

Q. Senator Bradley's bill on home care, S. 1016, requires that State or local agencies establish, within the context of Medicare, an ombudsman-like unit for investigating home care patient complaints. Should this function be established under Medicare or under the programs within the context of the Older Americans Act?

A. The Department's Office of Planning and Evaluation is currently funding a study to address that very issue -- to determine the feasibility of expanding the nursing Home Ombudsman Programs sponsored by the Administration on Aging to include oversight for home care services.

Under the Medicare program, we currently have the authority to respond to beneficiaries' complaints. The contract scope of work for peer review organizations (PROs) requires that PROs establish procedures to respond to beneficiary complaints. In addition, the Omnibus Budget Reconciliation Act of 1986 requires that PROs review all written complaints by beneficiaries about the quality of services provided. The PRO must also inform the individual of the final disposition of the complaint and provide the practitioner with an opportunity to discuss the complaint where there is a finding that care does not meet professionally recognized standards of health care. Regulations are being promulgated and implementation of this provision is projected for Fall 1987.

PATIENT OUTCOME DATA FOR HOME CARE

Q. How far along is HCFA in developing patient outcome data for use in assessing the quality of home care?

A. Before we can develop patient data to assess home care quality, we believe it is necessary to first change the orientation to surveying home health agencies. The process presently focuses on written compliance with the conditions of participation rather than on patient outcome measures.

We recently awarded a contract to ABT Associates, Inc., Cambridge, MA to develop a patient-centered approach, using outcome measures, for surveying home health agencies. This contract will be completed by 1989 and the results, along with results of other home care studies presently being conducted, will be used to implement a new outcome-oriented process to assess the quality of home health care. The new process will produce the patient outcome data necessary to develop more objective measures of quality care in home care settings.

INTERMEDIATE SANCTIONS FOR HOME CARE AGENCIES

Q. Currently, the only sanction against a home care agency that is providing poor quality of care is termination from the Medicare program. Shouldn't we establish a series of intermediate sanctions, fines, penalties, etc., to penalize poor performance?

A. Such sanctions are difficult to administer. Financial penalties may have the effect of causing termination, since many home care agencies serve primarily Medicare patients and rely on the Medicare program to finance most of the services provided. Imposing financial penalties can also raise the issue of potential skimping on quality when fewer funds are available. In addition, we want to avoid the imposition of Federal requirements which might undermine current State flexibility to correct deficient performance.