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THE FEDERAL-STATE EFFORT IN LONG-TERM CARE  
FOR OLDER AMERICANS: NURSING HOMES AND  
"ALTERNATIVES"

GOVERNMENT

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DOCUMENTS

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HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

NINETY-FIFTH CONGRESS

SECOND SESSION

CHICAGO, ILL.

AUGUST 30, 1978

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# THE FEDERAL-STATE EFFORT IN LONG-TERM CARE FOR OLDER AMERICANS: NURSING HOMES AND "ALTERNATIVES"

WEDNESDAY, AUGUST 30, 1978

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Chicago, Ill.*

The committee met, pursuant to notice, at 9 a.m., in room 204-A, Everett McKinley Dirksen Building, Chicago, Ill., Hon. Charles H. Percy presiding.

Present: Senator Percy.

Also present: Kathleen M. Deignan and Nancy M. Coleman, professional staff members; Jeffrey R. Lewis, minority professional staff member; Lawrence Grisham, legislative assistant to Senator Percy; and Theresa M. Forster, fiscal assistant.

## OPENING STATEMENT BY SENATOR CHARLES H. PERCY, PRESIDING

SENATOR PERCY. I am very pleased to convene this hearing of the Senate Special Committee on Aging and ask the witnesses who comprise our first panel to take their places.

I'd like to make an opening statement that will set the framework for this hearing and put it into perspective. However, before I do, I would like to announce that we are pleased and honored to have one additional witness. At the last minute, we were able to prevail upon the president of the Better Government Association, Marjorie Benton, to be with us this morning. I think we all know her as a civic and political leader in Illinois and in the Nation, and in the last year or so, her diplomatic endeavors as a delegate to the United Nations "Special Session on Disarmament" have overshadowed even her civic activities. She will be asked, if she would—I know you haven't had much chance to prepare for it—to make an introductory comment.

The Chair would also like to express appreciation to Terry Brunner, who has interrupted a long-planned vacation with his family. Generally, I would say that that takes precedence almost over anything, but the committee felt that his presence here today was absolutely essential, and we specifically—the committee—asked if he could interrupt that vacation. We're very grateful, Terry, that you interrupted your schedule; and to the members of your family, I want to express my deep appreciation on behalf of the Senate Special Committee on Aging.

This hearing was approved by the chairman of our committee, Frank Church, and by Senator Pete Domenici, the ranking Republican

member, and it is one in a series of continuing hearings this committee has held.

It's been our feeling that we made considerable progress from the early hearings that we had in Chicago in 1970, and I think corrective action was taken. However, the revelations that were brought to our attention by the Better Government Association investigators and by WLS television, the ABC affiliate in Chicago, caused considerable concern among those of us who have devoted many years to this issue. This hearing was called, then, to give an opportunity to the nursing home industry and to the State, local, and Federal Government to assess this situation.

I have had sharp criticism through the years from nursing home owners for my criticism of the industry. As recently as yesterday, I was confronted by a nursing home owner who said, "I am here from California. I'm going to attend this hearing, and I just want you to know that conditions are outstanding in California."

Well, the committee has held numerous hearings across the country over a period of 8 years. I offered to take him, if he had the time, right then and there, to a cross section of a few of our nursing homes that I know will not meet the kind of standards that we feel are necessary. He excused himself, saying that he didn't have the time for it right then.

We've been conducting a series of investigations into issues related to long-term care of the elderly; particularly institutional care. As I've mentioned, earlier this month, the Better Government Association and WLS-TV reported on the results of a 4-month investigation into the quality of care in some Chicago area nursing homes. This hearing is being convened as a result of that reporting.

I cannot help but think, as I have seen investigation after investigation by the BGA, that the concept for this organization went back a few years to when we really only had one-party government in Cook County. The last minority party member had just been defeated.

I was explaining to my son, Roger, who I had on a hunting trip at the time, why the two-party system is so important in order to have a check and balance in Government.

He said, "Dad, you've got no check in this thing now." I said, "That's right. Something ought to be done about it."

At that time, I contacted Roy Ingersoll, president of the Borg Warner Corp. The two of us formed a committee and raised \$100,000 within 1 week to entice the BGA to shift its emphasis from endorsing candidates in elections to opening an investigative arm. We went to everyone in the media, indicating that if they would assign investigative reporters, virtually unknown in those days for journalism, we would work closely with them. So, when the BGA works with news media, both entities assigning investigative reporters to the task, they are really promoting the two-party system of government, a system that really hasn't operated effectively and well in Cook County.

Again, on behalf of all of my colleagues that believe in a strong two-party government, we commend the BGA for what it has done through the years. It has set a striking example of what can be done when the spotlight of public attention is placed on problems in society.

Since I became a member of the Special Committee on Aging in 1972, I have personally participated in over 30 hearings on conditions

in nursing homes across the country. The activities of the committee have already resulted in significant improvements. For example, they have led to the indictment of some of the worst people I've ever dealt with in my life, particularly a couple in New York who have been jailed. The exploitation of the poor, particularly if they're elderly, was about the most reprehensible crime that I had seen, and we revealed sufficient information to convene grand juries at that time. Indictments were brought down and jail sentences were served by some people.

In another area of improvement, last year, the Medicare-Medicaid Anti-Fraud and Abuse Amendments Act was signed into law. This law will strengthen the capability of both the Federal and State governments to detect, prosecute, and punish instances of fraud and abuse in these programs.

In addition, in the near future, the Senate will consider the Medicare-Medicaid Administrative and Reimbursement Reform Act. This bill would simplify reimbursement formulas, make the U.S. Department of Health, Education, and Welfare the final certifying agency for nursing homes serving medicaid patients, and remove some of the restrictions which discourage the provision of home health care.

As many of you know, part of the purpose of this hearing is to discuss nursing home abuse. I first want to stress that I know there are many good quality nursing homes here in Illinois. During the 3 years that I researched and wrote a book called "Growing Old In The Country Of The Young," I constantly, in depicting some of the deplorable conditions I found in many nursing homes, a great many of them right here in Illinois, interlaced that with the good side of the story. Of course, all the attention and the headlines were given to the other side.

Just yesterday, I happened to visit again St. Joseph's Home for the Elderly in Palatine, Ill. This home is run by the Little Sisters of the Poor. It serves 200 residents.

It is such an outstanding home that when I took a poll of the people, over two-thirds of them didn't come from the area at all. They had heard about the excellent care. If every single patient left that home, there would be enough applicants on the waiting list to fill the entire home. Over 200 people are waiting to get in.

Over half of the residents have incomes below the poverty level and are receiving public assistance. There's not one iota of difference in the way they are handled.

Mother Celestine, who runs the institution as its administrator, advised me that public assistance only covers about 75 percent of the cost. Private contributions absorb 25 percent.

But this home, if anyone doubts that there can be good homes, is immaculate. It's beautiful. It's clean. The residents receive genuine loving care from the staff. The relationship between the staff and the residents is unbelievably fine.

I'm sure that there are many other such nursing homes. I've been in them across the country, and as we spotlight and focus attention on poor ones, we can just as easily find good ones that are well run, where people really care about the people that are in them. They're there because they want to help, not because they want to exploit and make a fast buck.

Unfortunately, as we saw in the BGA/WLS-TV investigation, abuse of patients continues to persist in some nursing homes. In its earlier investigations, the committee found unsanitary conditions, poor food, and poor food preparation in many nursing homes. These conditions still exist.

We found negligence on the part of nursing home staffs, negligence which often led to injury or death. These conditions often still exist.

We found that up to 40 percent of the drugs administered in nursing homes were given in error, either in the wrong dosage, or to the wrong patient.

We also found a disturbing lack of trained medical personnel in many nursing homes.

Although some improvements have been made, many committee recommendations, such as better training and of higher qualifications for nursing home personnel, have yet to be acted upon.

In today's hearing, I want to explore two issues, because many of you in the audience are experts in these fields: intergovernmental mismanagement of existing laws and regulations relating to the quality of care in nursing homes, and the necessity for alternatives to institutional care.

Who is responsible for monitoring, evaluating and certifying nursing homes? HEW has certain responsibilities. So do a number of different State agencies.

In addition, in many areas, various municipal and county agencies have also been involved in regulating nursing homes.

With so many bureaucrats in so many different places responsible for regulating nursing homes, why does patient abuse continue? It could very well be that we have too many bureaucrats doing too many different things.

Perhaps we need to streamline bureaucratic procedures and place a single agency in charge of regulating nursing homes.

Regarding alternatives to institutional care, Senator Pete Domenici, the ranking minority member of the Senate Special Committee on Aging, and I introduced legislation, S. 2009, designed to encourage the provision of home health care services.

This legislation would remove restrictions in the medicare and medicaid programs which discourage the provision of such care. Senator Domenici and I agree that legislation is long overdue to effectively assist older persons to remain independent in their own homes. Of the thousands of nursing home residents whom I have talked to, so many of them say they came to an institution as a final resort. They'd much rather stay in their own neighborhood, their own home. However, they simply couldn't do it. They needed some degree of attention and care.

We strongly agree, Senator Domenici and I, that home health care with available support services would be an effective and cost efficient alternative approach to institutional care.

In addition, we believe that a strong national home health care policy could work to deter unnecessary hospitalization and premature institutionalization.

In addition, the elderly nutrition programs, initiated by myself and Senator Edward Kennedy, continue to grow. It was only a few years ago that we both struggled on the floor of the Senate to convince

the Appropriations Committee to give us an experimental amount of \$1.8 million.

Today, that program has grown to \$300 million and is one of the most cost efficient and finest programs that Senator Kennedy and I have introduced.

Through the congregate meal service provided by many senior centers, elderly persons not only have the opportunity to receive a nutritious meal, but also, just as important, nourishment for the soul. They receive a welcome companionship to take away the loneliness that they find in their elderly life, their so-called golden years.

The meals-on-wheels program provides meals to those elderly and handicapped persons who are unable to leave their homes. When we first introduced this program as an experiment, just as I have visited hundreds of the congregate meal centers, I went out for a day on the Near North Side of Chicago and into Uptown and delivered meals-on-wheels to our recipients out there.

It was a thrilling experience for me, and I am happy to report that the Older Americans Act amendments, which recently passed the Senate with Senator Domenici's and mine and Senator Church's strong support, contained additional money to expand both of these nutrition programs.

Most elderly persons want to stay in their homes. We should be facilitating this instead of continuing programs and regulations which force them into unwanted and often unnecessary institutional care. This is not only better for the individual, but it's also less costly.

Improving the quality of nursing home care is a valid role of government. When owners and staffs of some nursing homes are negligent to the point of patient injury and death, tax dollars are being used in the most perverse sense. The human misery caused by patient abuse is appalling. The deception of families whose loved ones are abused in nursing homes is cruel. We simply must stop it.

We must stop funneling Federal tax dollars to unscrupulous nursing home operators. Illinois nursing homes received \$225 million in Federal Medicaid payments last year alone.

It is time that people began receiving better care for their money. We must consider possible actions. For one, I maintain where patient abuse is discovered in a nursing home, the owner should be put on probation for 30 days, under day-to-day monitoring.

If abuse persists, such as the failure to provide patients with a nourishing diet, then Federal funds should be cut off and the nursing home's license revoked. Patients and their families would then receive assistance in seeking an alternative nursing home.

The issues to be addressed today are very serious ones. Solutions to the problems which have been brought to our attention will require the enlightened cooperation of both Government officials and the community.

Whether the problems exists at the Federal level, in Congress, at the State level or at the local level, let's find out where these problems lie, and let's do something about them. We cannot allow these problems to persist. We must address these problems and develop some effective solutions.

We have new administrations in Washington, Springfield, and Chicago. The time is ripe now to involve these new administrations and move forward.

Through the years, I've worked with Mayor Bilandic, and I have seen some improvement. I also worked for many years with Mayor Daley, and sometimes I was pleased with the attention given to elderly issues, and sometimes not as pleased. I'd say to Mayor Bilandic, you have a new administration, and you have a gigantic number of problems to cope with.

What I think the Senate Special Committee on Aging is really saying to you, and I speak on behalf of every single member of that committee, just as we in the Senate have seen fit to create a special committee and move it to highest priority in the Senate—and I gave up the Joint Economic Committee, which I dearly loved, in order to serve on this committee—we hope the city of Chicago, under a new administration, will place the highest priority on these problems. We look forward to working with Mayor Bilandic, who is a humanitarian who's done a great deal for the city already, particularly in working with the elderly. I have been thrilled to see revenue-sharing funds diverted to building senior citizen centers in this city that would do credit to the finest that I've ever seen in the State of Florida.

I say to my friend, Jim Thompson, that he has a lot of problems and a lot of priorities. Everyone's after him for something; but I've had complete cooperation in working on this problem with him.

We're trying to focus new attention on the elderly, to develop a new sense of priority, Governor Thompson has outstanding administrators working on it. We want to hear from them today, but we're not here to criticize. We're here to assess. We're here now to say that we do have a set of conditions that should be better.

We're not holding anyone responsible for it today, but we will if we don't have corrective action a year from now. The same thing is true, of course, of the Carter administration. That is a relatively new administration and must also cope with a lot of problems. We just want to raise this problem to the highest level.

I want to thank every one of you for taking the time to attend the hearing this morning, and I especially want to thank our witnesses for taking the time from their busy schedules to be with us.

I would like to introduce members of the Special Committee on Aging staff who are here, and also a personal staff member of mine, Lawrence Grisham, who specializes in the field of education and health with me. He was just, and I'd like to publicly announce for the first time, selected by Ebony Magazine as one of the 50 outstanding future black leaders of America. I have found him to be one of the ablest staff members that I've ever worked with.

On my left is Jeff Lewis, a minority staff member, with whom I have worked very closely.

Kathy Deignan, Nancy Coleman, and Theresa Forster are members of the Aging Committee majority staff who will be here to help any witnesses or any other members of the audience equally interested in this problem, so that I can follow through on your queries and suggestions.

Now, that's what's known in the Senate as a filibuster. You ought to know what it's like when we start a hearing and we have nine members of the Senate, each of whom has an equally long opening statement. Sometimes we adjourn for lunch before the witnesses even start.

Mrs. Benton, we're honored to have you here this morning as our first witness.

**STATEMENT OF MARJORIE BENTON, PRESIDENT, BETTER  
GOVERNMENT ASSOCIATION, CHICAGO, ILL.**

Mrs. BENTON. Thank you, Senator.

The Better Government Association's recent investigation of nursing homes with WLS-TV is the most recent example of our commitment to monitor Government programs for the sick, the elderly, and the poor.

This is not the first time we've examined the nursing home industry. BGA investigations, in 1971 and again in 1975, revealed serious problems in nursing home care.

We launched our latest investigation to check on what progress had been made in providing care for the elderly. We were also responding to complaints from citizens who were concerned about their relatives and friends who had suffered abuses from unscrupulous nursing home operators.

Our findings confirmed the fears about the abuse and neglect of the elderly.

Public policy toward the elderly has advanced in recent years. Medicaid and Medicare provide the elderly with needed support, but money alone will not solve the problems we uncovered.

Despite an increase in expenditure for elderly citizens, the Government's response ultimately translates into the euphemism "Out of sight and out of mind." We must find ways to rely less on impersonal institutionalized residential care for the elderly. We should make every effort to make it possible for the elderly to stay with their families and in their own homes.

Of course, nursing homes will continue to be needed; they provide an essential service. But we must find ways to make the nursing home operators more responsive to the needs of their residents. They should not profit at the expense of the old and the poor.

We greatly appreciate the opportunity to testify here today. The Senate committee's effort is tremendously important. What you do will affect the lives of thousands of dependent elderly citizens. We don't envy your task.

Senator Percy, over the last several years, no one has demonstrated a greater commitment to improving the lives of the elderly than you have. Bold and imaginative leadership is needed to reform nursing home care. I believe that you can supply that leadership now as you have in the past.

And Senator, if you don't mind a personal note, I'd like to introduce my son, Scott, who is here today. He is going back to college at noon. He was an intern at the Better Government Association this summer, and he worked on this nursing home investigation. I just want to say to my son that I was very proud of his commitment and the kind of work that he turned out this summer. He's sitting right back over there.

Senator PERCY. Scott, I wonder if you'd stand up. [Applause.]

Mrs. BENTON. Now, Senator, I'd like to introduce J. Terrence Brunner, the executive director of the Better Government Associa-

tion. Terry will outline our efforts and recommendations, and he and our staff will answer any questions that you might have. Thank you very much.

Senator PERCY. Thank you very much.

**STATEMENT OF J. TERRENCE BRUNNER, EXECUTIVE DIRECTOR,  
BETTER GOVERNMENT ASSOCIATION, CHICAGO, ILL., ACCOMPANIED BY DAVID PROTESS, RESEARCH COORDINATOR**

Mr. BRUNNER. Thanks for all the nice, kind words. I think on behalf of the BGA, we ought to say right up front how we've appreciated—not only this year, but over the many years—the interest that you and the committee have shown for the care of the aging in Illinois, not only in the sort of hearings we had over the medicaid series in Washington, but those Sunday mornings when you and I went out cold and called on various nursing homes on the North Side and talked to people firsthand to find out what it's really like.

I don't think there are many public servants in this country who would take their valuable time to do that sort of thing, and certainly BGA has—we really appreciate it.

Senator PERCY. I might say sometimes we were not always welcome. We made a habit of not letting people know we were coming, and the door was barred at one time to us until I became rather insistent—that I felt the local police district would see to it that I got in unless they offered us the courtesy of investigating it.

But a surprise visit in a nursing home terrifies some operators. Some of them welcome us. Some of them are terrified by it because of the conditions you find when you walk in.

Mr. BRUNNER. Senator, today I have with me Dave Protes, who is our research coordinator, and Barbara Klein, who is an attorney on our staff and worked for a period of time in one of the nursing homes. She is going to testify to her experiences.

Also with us are Peter Manikas, Lee Norrgard, and Mindy Trossman. All had a part one way or another in the project; Peter Karl, from WLS-TV, led that project, along with Doug Longhini, who used to be with us and is now with WLS-TV.

I hope that the testimony today and the work of the committee will lead to substantial improvement in the lives of hundreds of thousands of nursing home residents in Illinois and throughout the country.

This March, the BGA and WLS Target Seven Investigative Unit began a 4-month probe of the nursing home industry in Illinois. The investigation was the second major inquiry into nursing home conditions known in a 7-year period.

Senator, I'm sorry to report that the quality of resident care in Illinois nursing homes continues to be grossly inadequate. Superficial improvements in the facilities have worked a cruel hoax on patients and relatives by raising their expectations above the facts.

The lives and happiness of our aging and ailing citizens have been subordinated to an assortment of profiteers, ill-trained, or disinterested professionals, and an invisible and ineffectual bureaucracy that spends billions but cannot even measure the quality of care delivered.

The questions are: How many newspaper and television exposés will it take before change is brought about in this industry? How many outcries of public indignation? How many public hearings? How many well-intentioned legislative reforms?

The instances of abuse and neglect we found in nursing homes are so fundamental and so wide spread that one is compelled to question whether nursing homes themselves are capable of providing good care.

There is no substitute, obviously, for tender loving care at home. Yet almost all of the Government incentives are for institutional care that is more costly and impersonal.

Caring for our elderly at home has become less and less the norm. Since the enactment of medicare and medicaid in 1965, the numbers of nursing homes and nursing home patients have proliferated. The Federal Government spends billions of dollars for nursing homes but comparatively little for alternatives to nursing homes: Day care centers, group homes, meals-on-wheels, visiting nurses. There are no tax benefits to assist families with the financial burden of a home-bound elderly loved one.

For a very high price, we have bought a public policy of killing our elderly by neglect.

Now, Senator, as you know, we have a long history of involvement in these issues. Our concern for the plight of nursing home residents is traceable back to 1971, when the BGA and the Chicago Tribune joined forces to investigate and expose shocking abuses in Illinois nursing homes. Our investigative reporters worked undercover in 20 nursing homes at that time and documented filth, inadequate food, patient neglect, and fraud.

Numerous governmental reforms were enacted in the wake of that 1971 investigation. Federal and State legislation strengthened nursing home standards and enforcement procedures, the State enforcement staff doubled in size, the Illinois Department of Public Health promulgated comprehensive new regulations in 1975, and the city of Chicago stepped up inspections.

Several of the worst homes were closed by the State, and others were voluntarily closed by owners after funding was withdrawn.

The investigation has been largely credited with prompting many of these reforms. Yet despite this overwhelming governmental and public response, the BGA committed its resources to a followup probe of nursing home operations in 1978.

Scores of telephone calls coming to our office and channel 7, letters reporting continued abuses and neglect in nursing homes, caused us to question whether these apparent reforms had been effective.

So this time, we went about choosing a little bit of a different methodology. Our investigation was even more in-depth than the original probe. This time, BGA investigators worked undercover in eight proprietary nursing homes.

Before going to work, each investigator studied the State regulations and the current law and literature on long-term care facilities. Our investigators didn't stay in the homes for just a few days. Our average stay was over 2 weeks. I think we had eight investigators totaling 13 weeks in nursing homes this time, whereas in the past we had people in for just a day or two at a time.

In some cases, we worked for more than a month in a particular home. Investigators worked in a variety of responsible positions as activity directors, social rehabilitation workers, nurses' aides, and cooks, as well as maintenance workers and orderlies.

Thus, we were able to minimize the possibility that the regulatory violations we witnessed were transitory or isolated occurrences. We were able to study nursing home operations from the inside from a variety of perspectives, and recorded our findings on the film that we'll see today.

Our on-the-scene observations were buttressed with an analysis of Federal inspection reports for 75 of Chicago's 89 licensed skilled and intermediate care facilities, and interviews with Government officials, nursing home employees, and community experts in the long-term care field.

The final report was aired in an eight-part series on WLS-TV between July 13 and 21. Millions of viewers in Chicago watched that series. This was one of the largest audiences in the history of Eye-witness News.

In fact, I think the initial night, Karl, was the highest audience rating they've ever had on channel 7.

Mr. Chairman, this is what we found. The grossest abuses are not as prevalent as they once were, and physical plants are improved. However, our study of State and Federal inspection reports reveal that 6 of 10 homes still violate personal care regulations, almost half provide insufficient nursing and medical care, and most are not prepared for medical emergencies.

Senator PERCY. How extensive a sample did you make to come to these conclusions?

Mr. BRUNNER. Well, that was on the basis, Senator, of 75 of the 89 reports on file with HEW. In other words, every one that was on file, we looked at, and that was buttressed, of course, by the eye-witness accounts that we're going to see on the film and from Barbara.

State inspections conducted under contract with HEW focus on "bricks and mortar"—the size, layout, and recordkeeping at a home, not on patient care. HEW has not even defined patient care standards for medicare and medicaid certification, even though nationally, HEW funds are half of all nursing home revenues.

Regulation by the eight State agencies with oversight responsibilities for nursing homes is characterized by overlap, lack of coordination, and buckpassing. Enforcement of regulations is so lax that not a single home was closed by the State last year.

What we saw on the inside was even worse. BGA investigators working in homes witnessed an 80-year old woman beaten and gagged by laughing nurses' aides, residents going hungry while aides ate their food, and administrators paying themselves more in salary than they spend to feed their residents.

We saw residents left in their beds all day and all night, lying in their own wastes; improper food preparation; inadequate control of drugs; and fraud in the charting of services not rendered.

Senator, I could go on and on reciting these abuses. I think the film tells that story better than I can. However, I only want to emphasize to you that the problems are as real as they are widespread.

We're also going to have more, as I mentioned, from Miss Klein on her firsthand experiences in the home.

Some of the recommendations—

Senator PERCY. Before you get into recommendations, could I ask whether you know of any other areas subject to certification inspection where the proportion is so high of failure to meet regulations?

Mr. BRUNNER. No, I don't, Senator.

Obviously, what disturbed us, or what we couldn't understand, was how the State of Illinois—in effect, the Federal Government—could sit with these reports done by their inspectors in their files showing that almost—you're talking about 75 of 89, I believe the number is, reports on nursing homes in which their own inspectors are telling them conditions are terrible, and yet nothing is being done.

We went around and looked and talked to the Government officials involved. They all said, "Well, gee, that's their problem. That's their problem." It was as if there were nine people in a circle all pointing to the next person in line, it being their responsibility.

There's a complete and utter lack of anybody accepting the responsibility, and these are not findings that we made. Our findings merely buttressed the findings of the State and Federal agencies involved.

Senator PERCY. In this case, the buck just doesn't stop anyplace.

Mr. KARL. I'd like to point out, too, that our investigation has been continuing, and when we went back to the Department of Public Health and reexamined some records, looking for other things, personnel from the Department of Public Health talked to our investigators and researchers, and said that they would have liked to have known that we were conducting this investigation because they could have told us about some homes that we could have really gone into and found a lot of things. Apparently, if the people in the various departments know that this type of thing is going on, it just bewilders me. As was mentioned in our report, not one home was closed last year.

Senator PERCY. The whole purpose that I found of public hearings, in 12 years as a Senator, is to flush out these things, to alert people that we are anxious to have this information, to let public officials know we're going to have a body of information soon on this that will be overwhelming, and that they better start to do something about it.

One other question, before you continue. You mentioned conditions of people who are bedridden.

Yesterday, when I talked with Mother Celestine, the administrator of the St. Joseph's Home for the Elderly, I asked her about the Illinois point system. I would like to advise the State officials that I will ask them for their judgment in this matter. They didn't create it. They're not responsible for it. They're just administering what is now the system. Mother Celestine indicated that, in her judgment, the system is set up to provide incentives for people to do exactly what shouldn't be done with the elderly.

She said, "We try to keep them active, out of bed, doing things. We have all kinds of activities, so that they will develop a good, healthy appetite, want good meals, and so forth."

The opposite seems to be the effect of the point system in Illinois, where the more bedridden patients there are, the higher the payment that is made to the nursing home.

Now, when we subpoenaed the records, we found a very high proportion of drugs or sedatives. Why were those older people given so many sedatives? They can't sleep because they're too inactive. A person sleeps after a day of activity. But if patients are in bed a great deal of time, they get bedsores, and the nursing home gets paid for more bedsores. You dope them up with sedatives, you don't have to feed them as much, you don't attend to them as much, you don't need as much care for them, and they just sit there like vegetables day after day, reaping profits for the unscrupulous owner.

Now, how do you overcome that? Do you find that this is a problem that we've got to cope with and that those people from the State, local, and Federal governments following you in the witness chair should respond to?

Mr. BRUNNER. Senator, one of the recommendations we make is that somehow we've got to take the profit out of the point system. We must change it around in providing incentives and rewards for quality care, as opposed to bad care or poor care or care which ends up with people being as sick as possible to get the most reimbursement.

I think that Barbara Klein is going to talk more about that in a firsthand way—her actual observations, what our testimony is all about. I think what we found this time was the fact, though everything looks a lot nicer than it did last time, the quality of care for people has not improved. That should be what we're really striving for, as you suggested, not the "bricks and mortar."

Senator PERCY. Why don't you just continue?

Mr. BRUNNER. Thank you, Senator.

I'd like to devote the remainder of my testimony to discussing the root causes of failure in nursing home reforms and recommending some avenues that this committee might consider taking to change the situation.

The most significant action the committee can take is to continue to press vigorously for alternatives to nursing home care, as you've suggested in the bill that you've sponsored with Senator Domenici.

For example, the Federal Government should consider tax incentives—loans and subsidies to families with elderly residents to help keep the elderly in their own homes.

Financial support for neighborhood projects that provide supportive services for the elderly is sorely needed.

We must act now to reverse the flow of Government incentives from institutional care to home care. Such a major shift in public policy cannot be accomplished overnight, so we must begin now to seriously experiment with a combination of strategies to improve home care.

Of course, there will always be a segment of our population for whom nursing home care is the only alternative. Nursing homes will continue to be necessary. Therefore, Government must set as one of its most urgent priorities the task of bringing nursing homes up to standards and making sure they stay that way. Any further delay is intolerable.

We concluded in our study that the major causes of failure in nursing home reforms are the lack of enforcement of existing regulations, the Federal Government's failure to develop meaningful guidelines for quality patient care, and a reimbursement system which

encourages financial abuses and cost-cutting at the expense of patient's needs.

I'd like to discuss enforcement, bureaucratic buckpassing, and delay that we found.

Illinois nursing homes are regulated, Senator, by eight State offices, 22 Federal offices, and several local agencies. The primary responsibility for inspecting nursing homes rests with the State's department of public health.

Now, HEW has delegated to them the responsibility for inspecting nursing homes to insure compliance with medicare and medicaid standards, but HEW's region V staff is only capable of validating 3 percent of the State reports.

With respect to intermediate care facilities which can only receive medicaid funds, HEW has completely abdicated any meaningful oversight or regulatory role. Federal bureaucrats perfunctorily approve the recommendations of the State for recertification. HEW says that since the State pays half the bills for medicaid in intermediate care facilities, the Federal Government has no jurisdiction.

Let me give you an example of how this abdication of responsibility works in practice. BGA investigators compared the HEW/State inspection report dated September 1977 for the Belmont Rest Home to the city of Chicago inspection report for the same period.

The HEW/State form listed only a few violations in recordkeeping. The city of Chicago report documented page after page of serious problems. HEW didn't even know that the Belmont Rest Home, an intermediate care facility, had been threatened with revocation of its city license.

We had our own investigator at Belmont. He kept a 50-page log of his 3 weeks as an activity director at the home. Among the things he saw at Belmont were rodents in the kitchen and a patient who burned herself with cigarettes while the staff at the home stood by and did nothing.

Even when serious patient care problems are documented by inspectors, nothing much is done about them. Reports full of abuses sit in the files collecting dust. Inspectors' recommendations for delicensure or decertification are almost uniformly overridden by departmental superiors.

Senator PERCY. Do you know if a State license has been revoked anywhere in Illinois this past year?

Mr. BRUNNER. No; we do not, sir.

Mr. PROTESS. In fact, none have.

Senator PERCY. Not a single one?

Mr. PROTESS. Not a single one.

Senator PERCY. This is like President Carter who, when I sat next to him, said there were 2 million civil servants in the country and only 226 out of 2 million had been dismissed last year for incompetence. What he didn't know is 142 of them since then have been restored to the Federal payroll with backpay. It appears we have here about the same sort of situation which called for civil service reform, which passed the Senate last Friday. That will shake up, I think, the Federal bureaucracy. Maybe it will shake it up here, also.

Mr. BRUNNER. Senator, so far the response of the agencies involved has been buckpassing, redtape, and delay. Everyone says that it is some other agency's job to enforce the laws.

Current proposals before HEW would have nursing-home operators inspect their own facilities, thereby further delegating authority from public agencies to the private sector. These proposals will only aggravate the problems we have witnessed.

The Federal Government must assume a more assertive and meaningful regulatory role with respect to both intermediate and skilled facilities. We're not advocating that HEW conduct routine inspections, but rather, that the Department be prepared to intervene when there is a void at the State level with a full panoply of remedies. If we need new laws to do this, let's get them.

I think that we'd like to focus for a moment, Senator, on a thing called QES. The Federal standards and State inspections focus on "bricks and mortar," not patient care. Implicit in this policy is the false assumption that if a home has the potential for quality care, quality care will be delivered.

Our investigators discovered that you don't have to look very deep beneath the surface of many first-class physical plants to find horrible problems. Now, HEW has no system for meaningfully evaluating the quality of care in a home.

QES—the quality evaluation system—is a survey procedure designed by an Illinois hospital to assess the quality of patient care in nursing homes.

In 1974, HEW gave the Illinois Department of Public Health a \$1 million grant to adapt and test QES as a regulatory tool in nursing homes. Everyone seems to agree that QES proved to be an effective means of assessing patient care in Illinois nursing homes, but QES isn't being used in Illinois.

The regional office of HEW says that QES doesn't tell them what the regulations say they need to know, even though they admit QES does validly measure patient care.

Washington officials of the Office of Nursing Home Affairs commended QES, but eventually yielded to the decision of the regional office.

Now, HEW hopes to come up with another quality evaluating tool by 1980. In the meantime, QES is sitting in the files collecting dust. "Bricks and mortar" inspections continue.

HEW should take a second look at QES. Patient care is too important for implementation of QES to be unnecessarily delayed. We also urge that comparative rankings of nursing homes be made available to every interested member of the public.

We have a couple of other suggestions, Senator, those being that obviously nursing homes should be dealt with by individuals who are personally interested and committed to improving nursing home care, and that they should be continuously involved in this operation.

Therefore, nursing homes receiving public funds should be required to establish, we believe, advisory boards composed of the residents' relatives, neighborhood leaders, health care professionals, nursing home personnel, as well as nursing home residents.

We further suggest, as I mentioned previously, that we've got to take a hard look at the point system in Illinois. We've got to come up with a point system that looks rather to quality care as opposed to financial incentives for people who are in the worst physical condition.

In conclusion, we'd like to say that the main thrust of our testimony today is that nursing homes do not provide substantially better care for the residents in 1978 than they did in 1971, despite numerous reform efforts by government.

Unfortunately, the improvements we've observed are largely cosmetic, primarily related to the appearance of the structure and facilities that house the residents. That's not to say that nursing homes have not changed, however.

The enormous expansion of governments' role in financing and regulating nursing homes has led to the creation of a massive institutional setting for providing care. The placement in nursing homes of the mentally ill, crippled children, and other dependent groups who have been removed from public institutions has significantly altered the face of the nursing home population.

In little more than a decade, many nursing homes have come to resemble 19th century almshouses for the poor. They have become institutionalized, publicly supported dumping grounds for society's castoffs.

Federal policy does not presently address this reality, which accounts for much of the governmental fragmentation at the State level.

We need a comprehensive national policy to meet the needs of our dependent population, more and more of whom reside in nursing homes.

This committee can help in the development of such a policy so that the bleak story of nursing home abuses shall not have to be told.

At this time, I'd like to again introduce Barbara Klein, who is a lawyer on our staff and had some firsthand experiences in a nursing home.

Senator PERCY. I'd like to say, from a personal standpoint, that Barbara Klein is well known to me. She served in my Senate office in Chicago. She did research and legal work, was an absolutely outstanding member of my staff, and I deeply resent her being stolen away.

**STATEMENT OF BARBARA KLEIN, STAFF ATTORNEY AND INVESTIGATOR, BETTER GOVERNMENT ASSOCIATION, CHICAGO, ILL.**

Ms. KLEIN. Thank you very much for those kind words, Senator.

From May 16 until May 29, I believe, I worked in the Ballard Nursing Center in Des Plaines as a nurses' aide, and I just want to describe to you a little bit of what I saw there.

I could only characterize conditions at the home as unconscionable neglect and lack of preparedness for any kind of emergency.

You mentioned earlier your questions about reimbursement. Well, we've been told by employees of nursing homes that it is not uncommon for nursing home personnel to label a patient in the entrance records or the nursing notes as belligerent when they are cooperative, forgetful when they are alert, or incontinent when they could use the bathroom with assistance.

At Ballard, I found that charting for range-of-motion exercises—which is a simple movement of the joints to keep the arms and legs as flexible as possible—were not given, but they were charted.

I also found in the home no towels or washcloths in any of the patients' bathrooms. Patients were often not kept clean and dry. Some were left all day and all night lying in their own wastes.

There was a lack of control of drugs in that there was, I think, what's called borrowing drugs, where the nurse will take a prescription from one patient and give it to another patient.

Senator PERCY. What's the purpose of that, Ms. Klein?

Ms. KLEIN. Well, it's for the convenience of the nurse. If they don't happen to have enough, say, liquid Valium in one patient's medicine chest, they will just take it from another patient's supply. There's really nothing harmful about it.

Senator PERCY. Do they keep the medical history of the patient receiving the drugs complete and adequate?

Ms. KLEIN. Well, I really couldn't say overall how this affects control of drugs, but it is a procedure that is not considered proper under the regulations.

Senator PERCY. Is it true that under medicare and medicaid simple things like aspirin are supposed to be covered in the basic costs, but the nursing home is reimbursed for all the costs of drugs?

Ms. KLEIN. Right. I'm not sure about that, Senator. When I was working at the home, one patient needed some talcum powder, and I went to the nurse and asked if there was any available. She said no, that that is something that they must supply themselves, and so there was no talcum powder for this woman who had a rash.

Senator PERCY. In other words, maybe talcum powder isn't allowable?

Ms. KLEIN. It is an extra.

Senator PERCY. As an extra cost. It's supposed to be in the basic cost, but the nurse simply said "We don't have it. It is up to the patient to bring it himself."

If we come to conclusions in these hearings, I'd appreciate hearing from somebody in the audience having different information. We want to make this record as accurate as we possibly can, and sometimes we come to conclusions that possibly are wrong. I certainly don't want to do that.

Ms. KLEIN. I suspect that perhaps aspirin and Tylenol are not included in the basic costs because most of these are only given to patients on prescriptions from their doctors.

The first night that I worked in the home, another aide left early, and I was left to care for 50 patients on the floor, 20 of them needing skilled care.

I had never had any experience as a nurses' aide before and, as I said before, this was my first night, so I did the best I could, but I think that's representative of the attitude of many aides, "Let someone else do it."

The nurses exercise very little supervision over the auxiliary staff and, in fact, in the home where I worked there was a problem in that some of the nurses were unable to speak English well enough to communicate with patients. When I had a problem with the patient and I went to the nurse, I had to give the number because they couldn't understand the name.

Senator PERCY. Is it also true among some doctors?

Ms. KLEIN. Not any doctors. I observed no doctors during my 2 weeks at the home.

Senator PERCY. If they'd had a legal problem, you might have been qualified, but if they had a stomach ache, you were not sure of what to do.

Ms. KLEIN. I told them when I started work I had been to 1 year of law school.

I told a patient there—he was so delighted—he said, “Well, can you help me get out of here, since you have some legal knowledge?” I told him to perhaps call the legal aid foundation and they would be able to assist him.

Senator PERCY. Well, when you were given such responsibility, the sole person in charge of the care of 50 patients, what time of day was that?

Ms. KLEIN. This was about 7:30 at night.

Senator PERCY. From 7:30 at night until when?

Ms. KLEIN. Until 11 o'clock at night.

Senator PERCY. Until 11 o'clock, the sole person taking care of 50 people, any one of whom might have had some medical problem at that time. What qualifications did you tell the nursing home you had?

Ms. KLEIN. Well, I told them that I had never worked in a nursing home before, that I was a college graduate with a major in philosophy and 1 year of law school and no medical experience of any kind.

I was very terrified when I was left to care for these patients, and I began demanding that some of the other aides assist me. This is when I observed the worst case of abuse and neglect in our entire investigation.

Two other nurses' aides came to help me put an 80-year-old woman in bed. She was somewhat upset about being put in bed and was cursing at the aides and myself.

They took her and slapped her, strapped her down in the bed in a posy vest. I noticed they slapped her on the buttock, which was inflamed with a rash, and they took pieces of Kleenex tissue and shoved it in her mouth and cursed at her—swore at her. Of course, while they were doing this, they were laughing and seemed to be enjoying abusing her, so that was the assistance that I got.

It was most disturbing to me my first night.

Senator PERCY. What was your salary when you were hired?

Ms. KLEIN. I believe I made \$3.50 an hour as an aide. That was the regular starting salary.

And I just would like to add that this was a first-class physical plant, a very modern, well-equipped nursing home, but when you look beneath the surface, you find there was one mop for three floors, there was no oxygen available on two floors, the nursing staff was very much overworked, and there were just quite a few problems.

Senator PERCY. Have you put into the record the name of this place?

Ms. KLEIN. Yes, I did. It's the Ballard Nursing Center in Des Plaines, Ill.

Mr. BRUNNER. Senator, if there are any further questions of Ms. Klein, what we'd like to do at this point is show you the film. It's undercover photographs taken within the home. I think it's obviously one of the best television pieces of its kind that's ever been done.

In the past, I think there's always been a criticism that, “Well, it wasn't really that bad,” this time, we've been lucky enough to capture on film through some very innovative techniques the actual television footage of what went on in these homes, and it's very revealing.

I'd like to turn it over to Peter Karl of WLS at this time.

Senator PERCY. I'm very grateful for this, because I was not here, and the members of the staff were not here, at the time of the showing of this film. I would very much like to see it.

I would suggest for those in the audience who cannot see the television screen, please feel free to come up anyplace. It's a short film. How long is it, Mr. Brunner?

Mr. KARL. Fourteen minutes.

Senator PERCY. Fourteen minutes, so just come up and stand anyplace that would be convenient to you, including right up here on the platform with us.

[Whereupon, a videotape presentation was shown.]

Senator PERCY. Thank you very much. If we could resume our seats.

I want to thank WLS television for that.

I've probably been in more nursing homes than almost anyone in the country, and the conditions depicted in the film are not exaggerated for many of the homes that I have visited.

The first question I'd like to put to Mrs. Benton is what prompted BGA to enter the nursing home investigation, and how did you come together with WLS television?

Mrs. BENTON. Senator, as I mentioned in my statement, this is simply a followup to earlier investigations, one we did in 1971 and again in 1975.

Recently, the BGA has tried to not just investigate and expose conditions, but to continually follow up and see if needed improvements in legislation are taking place. So with that philosophy in mind, we like to keep going back to investigations that we made to make sure that we're getting the results that we want.

I frankly cannot answer how this time we got hooked up with WLS. Maybe Pete can tell us how we did that.

Mr. KARL. I just received a phone call from a person who was very distressed about the lack of oxygen, and I went to meet with Terry. We were kind of hesitant at first because other investigations had been conducted, but then, as I think he mentioned in his opening remarks, we wanted to see if anything had been done. We were prepared at that time, if we devoted resources and time to it, if we could find that a lot of things had changed, that we would then report that or report whatever we found. We went to homes, and you saw the result.

Senator PERCY. What was the methodology used by BGA in selecting nursing homes for your investigations?

Mr. BRUNNER. Well, it was really done on a random basis, Senator. I think we felt as many other people did, before we began the investigation, that the situation in Illinois was probably pretty good.

As you know, since the 1971 exposé by the BGA and Tribune, there have been a lot of reforms and State publications with language indicating how good things were as a result of that investigation. There have been spot checks. You yourself had done them with us, and we really felt things were probably pretty good, so on a basis of looking at priorities and what ought to be investigated by an organization like the BGA, it wasn't nearly at the top.

Peter came in with this particular story of Alma Weny who died because of an apparent lack of oxygen, and we agreed with him to take

a look at that particular situation. But as we got into it, we kept putting more people into more homes and found it was very easy to get positions that were not just janitors, as we had in the past, or people working on the night crew, but people who were like Barbara—nurses' aides with responsible positions. What we did was leave the people in a lot longer than we ever had before in an undercover sense, and the results, as we've shown you, really were rather startling.

Senator PERCY. How many nursing homes did you actually investigate?

Mr. BRUNNER. Well, maybe Dave Protes, who is our research coordinator who directed it, would give you the exact numbers.

Senator PERCY. Would you identify yourself, please?

Mr. PROTES. I'm David Protes, research coordinator for BGA.

We, Senator, went into eight nursing homes, stayed an average of time of 2 weeks, although we stayed as long as a month. The homes were chosen in part out of the phone book, in part from tips from citizens who complained of conditions in those homes.

I think one of the important things to consider about those homes and about our working in them is that in response to a question that you asked earlier of Barbara Klein about her qualifications, we had seven investigators working in the eight homes. None of the seven investigators had any kind of experience or training in the health care field. None had any knowledge whatsoever how to deal with patient needs, yet they were immediately placed in positions of responsibility, and six of the seven investigators who worked in the homes did not even have reference checks. The one investigator who had experience in the nursing field ended up working a larger home.

Senator PERCY. Were any of the investigators put in a position where they had access to drugs or could administer drugs to patients?

Mr. PROTES. Yes; as a matter of fact, several were in that position. A very common condition was to have drugs left out in the open where either patients or any personnel, including nonmedical personnel, could administer them to patients.

Senator PERCY. In other words, if they'd wanted to be a pusher, they would have been able to get these drugs without a prescription? They could have used these drugs or sold them outside?

Mr. PROTES. Absolutely.

Senator PERCY. Could they have administered them to patients?

Mr. PROTES. Prescription drugs were left on carts in the hall unattended, where anyone could have easily obtained them and sold them elsewhere or administered them to patients themselves.

Senator PERCY. Mr. Brunner, in the text of your testimony you describe nursing homes as providing poor quality of care. I wonder if you could expand on what you consider to be poor quality care?

Mr. BRUNNER. Well, Senator, I think Barbara has indicated that her firsthand experiences—maybe Dave would like to elaborate on that point from the standpoint of the other investigative reports he directed.

Mr. PROTES. I'd say the main problem as far as quality of care goes is not so much a question of abuse, it's a question of inattention.

When patients need to have attention for anything, including going to the washroom, having their meals prepared, there's essentially two problems. There are not enough people around to meet those needs,

and second, the people who are available to meet those needs are untrained; 90 percent of the care that people receive in nursing homes in the Chicago area is provided by nurses' aides, and there are no standards that nursing home owners have to be obliged to follow for hiring qualified nurses' aides. Many of them are just high school students.

We often found that they were abusive in their treatment to the patients, but the main thing is that they were unqualified.

Senator PERCY. When I went into nursing homes, beginning, I suppose, 8 years ago, on an intensive basis, I found peeling paint, the stench of urine, and really despicable sanitary conditions.

When the word got out that I was in nursing homes virtually every weekend, and it spread rather rapidly, I understand there was a tremendous sale of paint. [Laughter.]

There was a lot of clean up and painting being done. In fact, it was seldom in subsequent weekends that I wouldn't go in and see painting being done on Saturdays and Sundays, on an overtime basis.

Maybe they were nonunion workers doing a little off-duty work. I'm not sure, but I do know that there was an awfully lot of painting.

Now, the cosmetic improvements were done. Are the physical facilities somewhat improved, or much more improved, than they were before?

Mr. PROTESS. We found that perhaps the single most important change in nursing home operations in terms of improvement were the cosmetic changes in the "bricks and mortar" sense.

Nursing homes looked better. The physical plant is generally cleaner.

On the other hand, that creates additional problems, because these changes have often been superficial and have nothing to do with resident care. People who were often thinking of placing a resident or family member into that home were tricked into thinking the home is a quality home and provides quality care.

There is a substantial difference between a quality physical plant and health care center that meets residents' needs.

Senator PERCY. Now, the eight homes that you picked on a random basis to make thorough investigations, spending a couple of weeks in each one of them, how many would you say were classified by your own definition as providing poor quality care?

Mr. PROTESS. I would say all of them provided poor quality care. In fact, we found numerous instances in each one of the homes that would cause the State, under its own regulations, to remove the license or the certification for the home. Yet not in one case, in any of the homes in the State of Illinois, was that done.

Senator PERCY. Now, I have testified on there being good nursing homes, and I've tried to really balance that out as an incentive for others and to prove that all is not despair.

Could any of you comment on good homes that you have been in to balance this record out and indicate the prevalence of them? Also, is there a great problem in that the Federal Government is not providing sufficient money to enable a nursing home operator to meet all his expenses and still have a reasonable profit, which I support—that a reasonable profit should be obtainable in a proprietary nursing home?

Mr. KARL. We went into the home that you talk about, except we went to the one in Chicago, Little Sisters of the Poor, St. Augustine's. They are a not-for-profit home, as you're aware of.

Senator PERCY. That's right.

Mr. KARL. The conditions there were unbelievably clean. The patients all seemed to be relatively happy.

The same cameraman who did our undercover work is also the cameraman who went there. We went unannounced, came in and talked to the nuns, told them we'd like to do a story right about mealtime to see how they were preparing meals. We were welcomed and went in.

After talking to the nun, Sister Madeline, we found that the not-for-profit home operates with a half a million dollar deficit every year. The amount of money that they spend on a breakfast meal, for example, would equal what most homes spend for all three meals.

We also talked to her about the types of people that were on her staff. They have 13 or 16 nuns who receive no salary from the nursing home whatsoever. They run a half a million dollar deficit without paying any administrative or any major costs in terms of personnel, and they provide a good service.

And I'm sure that there are other nursing homes that provide good service. We took our sample and we went into the homes, and we just reported on what we found in the homes that we went into.

Mr. PROTSS. But I think it's important to point out that in addition to the eight homes we were in, we also reviewed virtually all the inspection reports for all homes in the city of Chicago and that those homes contained numerous findings made by the inspectors themselves that indicate tremendous inadequacies.

Senator PERCY. I haven't reached a conclusion yet on whether we've gone the wrong route on proprietary homes. I came out of the private sector, and I happen to believe that incentives and so forth are adequate many times to provide goods and services to this country.

I have been in some good proprietary homes, and to the members of the Nursing Home Association here today, the professionals in that field, I cordially invite you to give us the names of some of the proprietary homes in the Chicago area that you are proud of, that can be inspected at any time of day or night. I invite the investigators to take a look at some of those homes.

I have been in some that were very good, one in particular on the Northwest side, which is run by a Czech refugee driven out of his own country, who has a dedication to taking care of old people. He operates an extraordinarily good nursing home and makes a profit on it.

So I wouldn't want to come yet to the conclusion that we went the wrong route, because it would be terrible to abandon the whole thing. What we want to do is make it better.

As a result of your investigation, is it your opinion that there is a preponderance of poor quality nursing home care in the Chicago area?

Mr. BRUNNER. Yes, certainly, Senator.

Senator PERCY. What types of reactions have you received from the general public?

Mrs. Benton, you have a broad contact with the general public. What reactions have you had back from people, and others of you, also?

Mrs. BENTON. I think, again, people are appalled and dismayed at how our society handles its elderly. I think there's been a certain amount of, "What can we possibly do to right this?" And I think for the first time, the BGA has come up with a list of recommenda-

tions that might finally make the difference in how we can take care of the elderly in our society.

The response of our board has been—we've been very proud of this investigation, very proud of WLS-TV, and I think the response we've gotten, the phone calls and letters and financial support for the BGA, has been very, very encouraging.

Mr. BRUNNER. Senator, I'd like to add one other point. I think that, as you know, I've been at the BGA for 7 or 8 years now, and it's very discouraging to have done an investigation like this and had the sort of results we've done and seen the reform and then go back out and see it all over again. Therefore, I think that the sorts of recommendations we're suggesting this time are in line with the kinds of ideas that are in the bill you mention, by yourself and Senator Domenici—an attempt to go a different route to come up with some other sort of solution other than to say, "We simply need more regulation." Obviously, we've gotten more regulation, and the standard of medical care within these homes has not improved. So what we're trying to do, as I'm sure you on the Committee on Aging are trying to do, is grasp for other solutions to the problem.

It becomes very apparent that the whole idea of putting older people in institutions is intrinsically not a very good one in comparison with keeping them in their own home. Yet all of the incentives are in that direction. Therefore, the recommendations which we made, I think, are those of an organization that's come up and found that our previous ideas that we suggested, many of which were implemented by the State and Federal governments, didn't really work very well to solve the problem.

I think that Peter Karl ought to comment from the standpoint of the media on the public response to the series, which was your question.

**STATEMENT OF PETER KARL, INVESTIGATIVE REPORTER,  
WLS-TV, CHICAGO, ILL.**

Mr. KARL. I think that we, in our newsroom, haven't had a response to anything like we've had a response to this, and we're continuing to get calls.

One of the biggest concerns that we have found from the callers and the letters that we have received—some against the series, saying that we weren't being objective and that type of thing—but the biggest concern I think that people have is that when they have to face the reality of placing someone in a nursing home, that they don't exactly know where to go. They go to the government offices and say, "Well, here's an inspection report," and they say, "Go take a look at it." You have to make your own decisions, because there's no way to rank the nursing homes.

I think we tried to point that out. This is what QES at least attempts to do, and people are very frustrated. They can go to a nursing home and they can see the first floor where most of the ambulatory patients are, and that type of thing, and feel that this is a good nursing home, but only find that they could be dismayed in the future.

I don't want to sit here and say there are no good nursing homes, either. I've been in several that were outstanding. The question, I think, is the motivation of the staff, and I think that that's one of the toughest things to do in order to provide good quality care.

The people, though, that call us really have a hard time determining how to find out if the quality of care is good and if the home itself is good.

Senator PERCY. When people call in and talk about problems that they're having in nursing homes, where do you refer them? Is there one agency that you can turn them over to that can help them?

Mr. PROTESS. There is no such place right now, Senator. There is a largely voluntarily staffed ombudsman within the State office of aging but the information is that that ombudsman is not related to the quality of care nursing homes in Chicago can provide.

If a citizen in the city of Chicago wants to find out how good a particular nursing home is, he has no place to go to find that answer.

If he goes to the city of Chicago and asks to see public inspection reports, he'll be told the public inspection reports made by the city of Chicago are not a matter of public record and not accessible to him.

I think the single most important problem that people have in trying to evaluate nursing home care for the people that they're considering placing in a nursing home—a family member, a loved one—is that there is no place for them to go.

Senator PERCY. You mentioned the nursing home run by the Little Sisters of the Poor right here in Chicago, the same group that runs the one in Palatine.

I've been in that home. It is immaculate. It is beautiful. A great deal of work through the years has been done to keep it up. It is an older building, but far more serviceable and livable than many of the newer buildings and structures that meet the building code for this type of facility.

Now, the problem is the code has been written in such a way that that building must be now abandoned, and the beautiful structure given up because it's one floor too high or something of that kind. There are certain standards, safety standards, that it does not now meet.

It's being sold, as you know. Government regulations require that it be abandoned, and the Little Sisters of the Poor have to raise money to build a new structure.

There are strong feelings that this building should not have been abandoned, that there should have been some flexibility in the regulations.

I have received several notes, one from a paralegal assistant that says:

Barbara Klein is telling it very well. I have worked in hospitals and am a paralegal with the Champaign County Legal Assistance Foundation, plus I have 2 years of nursing and have worked in nursing homes myself. Often I, as a nurses' aide, was left alone with close to 200 people by myself. Thank you. Carol Krawier.

I also have a note from the Champaign County home stating, "The State has just started to look through and revise the point counter system."

Mr. KARL. Senator, one other thing, if you don't mind me interrupting you, is during the course of our investigation, time and time again, one of the things that we have found is that when inspectors on the State level come to a home, there always seems to be knowledge beforehand that the home is going to be inspected—several days beforehand.

Though many people in the administrative positions say no, we have talked to many former administrators and people who have worked in homes, and they have indicated to us that when inspectors are coming, somehow the home knows.

Senator PERCY. We will put those questions, and Mr. Grisham, if you will draw up the questions, to the witnesses who will appear this morning from the State, as to what they have done to prevent it, because audits should be without notification.

I served on the Audit Committee of the Harris Trust & Savings Bank, and any employee who advised any department head that we were coming in on a Tuesday night at 8 o'clock to audit that account would have been fired. It would have been absolutely a breach of ethics for them.

An audit has to be a surprise. That's the whole nature of it.

My inspections have to be surprise inspections. No one was ever notified when I was coming to a nursing home. It's ludicrous to have inspections with plenty of advance notice. They can always clean the homes for 24 hours, until the inspection is over. Then they go about their ordinary sort of business.

I would like to ask the staff if they have any further questions; Jeff?

Mr. LEWIS. I have one question to Barbara.

Barbara, did you find it was true that the foreign nurses—could they also read English?

Ms. KLEIN. Well, the only reading that they seemed to have to do was the drug prescriptions, because their jobs seemed pretty much limited to passing out drugs.

Some of them who—many of the nurses where I worked came in on a temporary basis. They weren't permanent employees. They might come in one evening a week or fill in for someone else. There was a great deal of that, and so even though I looked through medical files for patients in the homes, I couldn't see whether they were able to write English, whether they were able to keep up with the progress notes, so I really can't answer the question from firsthand knowledge.

Senator PERCY. Thank you very much.

Any questions? [No response.]

I want to thank all of you. Sometimes, as you drive home, you think "If I only thought of that to say." If you do so, just put it in writing, and I will hold this record open for any subsequent statements any of you would like to make to amplify your comments.

I will not insert in the record at this point a correction I have received, or comment, from Lynn May, because he is a witness on the next panel. I'll put it in the record at that point.

If you'd like to stay on, we would like to find chairs for you to sit as near the front as possible.

I wonder if members of our staff could make available chairs in the front row here for our first panel.

Fine. The witnesses from the next panel will be leaving, so you can just take their chairs, if you like.

The chair would call now as witnesses Lynn May, Hugh Canaday, Richard Waltmire, James Scheibly, Suzanne Weiss, and Dean Jost.

We're going to recess for 3 minutes while we change our tape and we remove the equipment.

I would like to thank ABC television very much for providing the videotape for us. It added greatly to the hearings.

[Recess.]

Senator PERCY. We will resume our hearing now, and I'm going to ask our witnesses, because we have taken an unusual amount of time for our first panel, if you could limit your statements to 5 minutes or less. Obviously, your full statement will be put in the record as if given in full, and then that will allow us a little more time for questions.

Mr. May, I wonder if you'd mind just commenting in your opening statement on the question that you gave to me here.

Why don't I just read it into the record:

Nursing homes do not prescribe drugs. A physician must do so.

Reimbursements for drugs for medical payments is made to the pharmacist, not to the nursing home. Thus, the nursing home receives no financial benefits from prescriptions filled.

Could I ask the previous panel if they ever had any evidence that there was collusion between the nursing home owners and drugstores, and whether there was any incentive for the nursing home owner, through joint ownership or through kickbacks or sharing of profits, for them to prescribe drugs that were paid for by the Federal Government?

Mr. PROTESS. You want me to do it up here?

Senator PERCY. You can do it right from there.

Mr. PROTESS. We didn't find that. We were not in a position to find it, however.

I think it's important to be aware, though, that in Illinois, in the past year, there were a number of Federal indictments against nursing home owners for accepting kickbacks from a pharmacist, several of whom were prosecuted successfully, one of whom, in fact, was the owner of a nursing home that we had an investigator in. We heard regularly that they were cleaning up their act for a period of time because of the pressure from the Federal level.

That's the thing that we heard over and over again, but we didn't have any direct evidence of that.

Senator PERCY. Well, the evidence, I think, was available to many of us. It was available to this committee that that did occur.

We'll start with Mr. May as our first witness, and we welcome all of you very much.

**STATEMENT OF F. LYNN MAY, EXECUTIVE DIRECTOR, ILLINOIS HEALTH CARE ASSOCIATION, CHICAGO, ILL.**

Mr. MAY. Thank you, Senator Percy.

When the Better Government Association and WLS-TV issued their report, I did meet with Terrence Brunner and Peter Karl. I tried to get the full nature of the facts they had—the information that they had.

Senator PERCY. I'm sorry. Could you, for the record, identify yourself?

Mr. MAY. I'm sorry, certainly. I'm Lynn May. I'm executive director of the Illinois Health Care Association. We represent some 300 long-term-care facilities, both proprietary and nonprofit.

Senator PERCY. Both proprietary and nonprofit?

Mr. MAY. That is correct.

I was unable to obtain a complete list of the allegations or the facts in the case from the Better Government Association or WLS-TV. They indicated these would be coming out in the reports, and there was an indication that perhaps they'd be issued on white paper in the future, but seeking to find out more information, I received permission from the facilities implicated in the BGA report to send administrators from my association into these facilities to try to really determine the nature of the allegations.

And while these facilities were not members of our association, they readily assented to admit our people in, make their records available, answer any questions, and make their employees available to us. We found a pattern in the nature of the BGA allegations, we think, that largely, although not all, many of them were based on hearsay or incomplete exposition of actual facts.

For example, there were indications of abuse or mistreatment of individual patients. We checked on the allegations themselves. We found at times that the people who were supposed to be involved in the mistreatment were not working at that time, or the others had outstanding records of patient care.

In regard to the incident about serving cheese sandwiches on stale bread, we went back to the records and also talked to the dietary people of that facility and found that not only were cheese sandwiches served, but they were served on fresh bread that was delivered daily, and the menu also included hot soup, vegetables, dessert, salad, and a beverage.

So, I think that there is a general pattern here that there's a lot of sound and fury in the BGA report, but very often it doesn't hit upon actual events.

I'm very concerned about their exposition of the incident in Brookwood. They have no proof that that woman died as a result of not receiving oxygen. She died from other causes, and even today, they have not—

Senator PERCY. Do you have proof of those other causes?

Mr. MAY. Yes; they can be obtained through a death certificate, sir.

I'd also like to comment on the nature of the television coverage for the BGA study. I think it has to be faulted for too little factfinding and too much reliance on the exploitation of the visual impact of infirmities and debilities of the aged residents in the nursing homes. The disease, neglect, the vicissitudes of life have caused many of these people to become or to result in the poor health that they're currently in. Their life in nursing homes did not necessarily lead to this condition.

In fact, very often, the very environment that they can exist in, or perhaps show an improvement, is in a nursing home. I'm sure many people were shocked at what they saw in that film compilation, but the shock, I think, arises from a sudden confrontation with the disfigurement and ailments of old age and not necessarily is that prima facie evidence of poor care delivery, and I think that the television coverage should be faulted for that reason. At least there should be some question as to the nature of the journalism involved.

Now, I do not mean to portray that the BGA and WLS reports were completely groundless. We did have admission that some of the allegations were factual, that there was indeed poor judgment shown by staff, particularly in the nature of restraints that were ordered for patients or other aspects of care, but I think there's a very limited

number of actual events that could have been proved and were shown in this report. Yet the investigation went on for over 4 months, so I think the conclusion of our summary or investigation indicates there are some specific allegations of BGA really that don't demonstrate overt abuse by providers as much as they reflect the misunderstandings and realities of long-term care.

Now, while we found much error in the BGA allegations, we support most of its recommendations for improved long-term care in Illinois. We, too, believe that State regulations are chaotic, jumbled; confusing, often contradictory.

A forthcoming study mandated by the Illinois House of Representatives, I think, will show this very clearly, that there are too many agencies trying to do too many things, and the result is a wash. It doesn't achieve much.

One of my members recently furnished me a journal where over a 6-month period, every 2 days out of 5 there was some kind of survey or inspection going on in his facility, taking away staff time and nursing care time from their duties, and most of it doesn't really achieve much.

Now, we believe that the Thompson administration has recognized this fact, and they have taken the first steps toward correcting it, and my association has drafted legislation which we hope to introduce in the State next year which will require consolidation of surveys, so that they're more meaningful and useful.

Now, we also concur with the BGA that most or many of the existing Federal and State laws are cosmetic, and we really need to address the root of problems dealing with level of care.

One of the things that we have been working with the department on aging in the Lieutenant Governor's office is development of legislation that will mandate nurses' aide training, not only the training itself, but will provide funding for that.

Now, we think it's true, nurses' aides which make up the large bulk of employees in the nursing home, who have the most direct relationship to patients, are not trained at this time. We feel that a nurses' aide training program that is flexible, is fully funded, will provide immense benefit to the patients, and will help our industry do a better job.

We're also negotiating and talking with public health officials to develop legislation that will permit evaluation of patients where there's a clear and present danger to their safety and health. Currently, the State feels it cannot act, and there are difficult legal problems involved, but we think there is a solution so the State can act and take action in cases like this.

We're also interested in translating current patient rights regulations existant in Federal rights and translating them into State legislation. Now we worked to defeat a bill that would have done more than that in the last session of the legislature, but some of the patient rights that they wanted to establish were just clearly unobtainable.

We think it is necessary, at least to translate the Federal rights into State law and protect those residents of facilities that are not covered by medicaid or medicare.

Finally, as already has been mentioned, we have been working for many months now to develop an effective patient assessment tool that will assess patients' needs and provide the level of care necessary.

The Federal Government and the State have been working on these for many years. It's very difficult to really determine and measure the quality of care. We think we've made a really good start along those lines, and we hope that we're going to develop an effective program.

We wholeheartedly support the BGA's recommendations perhaps to provide alternatives to institutionalized care. Elderly citizens need the wherewithal to stay in their own homes as long as possible. However, we do not believe, as some studies have shown, that alternative care would necessarily reduce the rolls of nursing homes. In effect, I think it's going to open up a whole new kind of care to constituents that probably need it, that probably would not go into homes if they had some alternatives, but it isn't going to affect the rolls. It's going to be very expensive, very expensive, and we're concerned that in the rush—a very popular political move—to develop these programs, in an era of limited resources, that we're going to see a diminution of support of maintenance of elderly nursing homes.

I also agree with the BGA that there's a need for greater public involvement in nursing homes. We intend next year to implement a pilot project of establishing advisory councils along the lines that they recommend for our membership.

We've just started this, and I can't give you any timetable right now, but we think it's an idea that's worth exploring.

What we've found, however, is that in rural and suburban areas community involvement is good, and the neighborhoods are far away; where close family ties do not exist, you don't have it, and no matter what you try to do, you try to achieve it.

There's one final thing that I don't think the BGA really went into.

Senator PERCY. I think this is the third final point you've had. I'm going to ask Mr. Grisham to advise us when 4 minutes are up for each of our witnesses. Otherwise, we just won't get to the questions at all.

Mr. MAY. I'm sorry, Senator. You're right.

Senator PERCY. You'd make a great Senator in a filibuster.

Mr. MAY. Can I have 2 more minutes to address this issue?

Senator PERCY. Would you split it in half and make it 1? You've been going for 10 minutes now.

Mr. MAY. Fine. The BGA did not really look into the question of reimbursement.

The State of Illinois reimburses medicaid patients at the rate of \$19.50 per patient a day. They also support their residents in penal systems at \$17.50 a day. If there is a cost—

Senator PERCY. Let's not forget that 65 cents a day one nursing home is paying. Those are actual records, 65 cents a day.

Mr. MAY. Nevertheless, Senator, the cause of lack of care and the economic base of that has to go back to the State, to the Federal Government, and failure to adequately support and provide levels of care to the patients in long-term care facilities.

Senator PERCY. You're not testifying that 65 cents is the State allowance for food, are you?

Mr. MAY. No, sir, I'm not.

Senator PERCY. That one case is an isolated case.

Mr. MAY. Yes, sir.

Thank you.

[The prepared statement of Mr. May follows:]

## PREPARED STATEMENT OF F. LYNN MAY

Approximately 1 month ago, the Better Government Association (BGA) of Chicago, and WLS-TV, channel 7, announced that they had jointly conducted an undercover investigation of several nursing homes in and around Chicago and found conditions to be "horrendous." During the week-long reporting period, they alleged a number of instances of poor health care delivery or outright abuse of patients. The BGA went on to state that it saw little improvement in nursing home care since 1971, the date of its earlier investigation of long-term care facilities.

I subsequently met with Terrence Brunner, executive director of the BGA, and Peter Karl, the WLS-TV investigative reporter, to obtain more information about their allegations. I urged them to release the full details of their study to me so that we could work together to resolve the problems that they had uncovered, but they declined, indicating that they would issue a report in the future describing the many abuses they claim to have witnessed.

In the meantime, I arranged for several nursing home administrators who are members of the Illinois Health Care Association to inspect most of the facilities implicated in the BGA investigation. While not members of the association, most of these facilities readily agreed to our survey and gave our people free access to records and employees. We found that many of the BGA allegations appeared to be inaccurate or were incomplete expositions of actual events.

(1) For example, one facility was accused of only serving cheese sandwiches on stale bread for lunch. In fact, the documented lunch served in that facility on the day in question included cheese sandwiches made with fresh bread, soup, hot vegetables, dessert, and a beverage.

(2) Two employees of another facility were accused of striking and gagging a resident. Documentation showed that one of the employees was absent the day of the alleged occurrence and that the other one had an excellent record with the patients.

(3) An employee in a third facility was seen smoking marijuana. That employee was summarily terminated, a fact that was not mentioned by the BGA.

As for the televised coverage of the BGA study, it must be faulted for too little factfinding and too much emphasis on the visual impact of the debilities of aged and infirm residents of nursing homes. Disease and neglect reduced many of the people shown to poor health long before they entered nursing homes. Many of these were confused or incompetent. Several had to be restrained by doctor's orders for their own protection. I am sure many people were shocked by the images they saw, but this shock arises from sudden confrontation with the ailments and disfigurements of old age. They are not, however, prima facie evidence of improper care.

I do not mean to portray the BGA/WLS-TV reports as completely groundless. There were reported instances where facilities admitted to bad judgment on the part of staff, like inappropriate restraint of a patient or use of unnecessary force. But the limited number of these transgressions belie the universality attributed by the BGA. The conclusion of our investigation indicates that the specific BGA allegations do not demonstrate proof of overt abuse by providers as much as they reflect misunderstanding of the realities and exigencies of long-term care treatment.

While finding much error in the BGA allegations, we support most of its recommendations for the improvement of long-term care. We too believe that State regulation of nursing homes is ineffective and chaotic. A forthcoming State study of long-term care regulation mandated by a resolution of the Illinois House of Representatives will document the inefficiencies of this bureaucratic nightmare. Currently, one agency funds welfare residents, another licenses and inspects facilities, a third interprets fire and safety codes, and so on. Not long ago, one of my members furnished me a 6 month's journal which he kept in his facility. It showed that a Federal or State inspection of one kind or another was in process on an average of one out of every 2½ days. The cost of this wasteful bureaucracy to the providers and the taxpayers is incalculable. We believe, however, that the Thompson administration has recognized this problem and is taking steps to improve it at the State level. My association has drafted, and hopes to introduce next year, a bill which would require the development of a single survey instrument to be used by all State agencies regulating long-term care facilities.

We also concur with the BGA that many of the existent Federal and State laws and regulations affecting nursing homes are cosmetic, addressing only the physical nature of facilities. We believe that regulation should be directed at improving the quality of care, not paper compliance with irrelevant regulations. Accordingly, we have developed a bill in cooperation with the State Department on Aging

to mandate and fund nurses' aide training, which would enhance the performance and professionalism of the employees who make up the bulk of the work force in a nursing home and who work most closely with the patients. We have also held exploratory discussions with public health officials to develop legislation which would permit evacuation of patients where a clear danger exists to their health and safety. We are also interested in translating current Federal regulations requiring patients' rights into State law, and thereby protecting those residents in facilities that are not participants in medicaid or medicare. Finally, we are meeting on a regular basis with representatives from State agencies and the Governor's office as well as other provider organizations to develop an effective patient assessment tool to eliminate the cumbersome point count system which was justifiably criticized by the BGA. We believe that this effort will ultimately produce an evaluation system which will accurately determine patient needs and assign appropriate levels of care.

IHCA wholeheartedly supports the BGA's recommendation for more programs to provide alternatives to institutionalized long-term care. Elderly citizens should be encouraged to remain in their homes as long as possible. However, we question whether alternative care will greatly reduce the numbers of residents in long-term care facilities. We suspect that only a relatively small percentage of current residents could return to their homes under any circumstances. Rather the alternative care programs could service a new constituency which need home health care as a check on early debilitation. The cost of home health care is high if all the elements like visiting nurses, meals, transportation, etc., are included. We are fearful that in an era of limited tax revenues that a rush to alternative care will limit resources necessary for the maintenance of nursing home patients.

Despite our concerns, we advocate more alternative care programs. We also urge that rational, effective regulation of home health care programs be expedited by Federal and State agencies before fraud and scandal vitiate the public's tolerance of these programs. We also urge the amendment of Federal regulations to allow proprietary concerns to participate in title XX programs. Proprietary nursing homes, particularly in rural areas, could serve as the most efficient and qualified agencies for delivering a visiting nurse and meal services.

We also agree with the BGA that there is a need for greater public involvement in nursing homes. We have found that in rural and suburban areas community participation in volunteer programs and other activities is usually high. However, the lack of nearby neighborhoods and the absence of close family ties greatly reduces this involvement in large urban areas. We plan to implement a pilot project next year among the members of our association to examine the feasibility of the BGA's recommendation for the establishment of advisory boards comprised of residents' relatives, community leaders, nursing home personnel, and nursing home residents. We are hopeful that this experiment will lead to meaningful public participation in long-term care.

There is one glaring omission in the BGA's analysis of nursing homes in and around Chicago. It failed to explore the economic basis of long term care facilities and its impact on the quality of care. Approximately 70 percent of all long-term care residents in Chicago are supported by medicaid. Another 10 percent or more depend on medicare. Government reimbursement levels, established by law and regulation, are an overwhelming factor in determining the amount and effectiveness of long-term health care. Today the average medicaid reimbursement in Illinois is \$19.50 per patient per day. The State also spends \$17.50 per day to support prisoners in its penal system. If long-term care delivery is inadequate, the Federal and State governments must share the blame for failing to provide funding beyond a minimal level.

Several years ago, the U.S. Congress effected Public Law 92-603, which mandated that medicaid reimbursement must be "reasonably" cost-related to insure sufficiency of care. In March of 1978, HEW approved an Illinois reimbursement plan which only paid for costs at the 50th percentile of all facilities. The State, according to Governor Thompson, implemented this plan to meet its budgetary restrictions. The plan is forcing care down to the median level. It is compelling facilities to deliver mediocre care in order to stay in operation. While making allowances for differences in efficiency levels, in general, facilities which spent more on their patients now must spend less, while facilities which spent little are being reimbursed over and above their costs. While the Illinois plan is particularly restrictive, the pattern is the same elsewhere. HEW and the State governments have evaded the intent of Congress by implementing reimbursement plans which superficially meet the requirements of Public Law 92-603 but

undercut the welfare of long-term care residents and shortchange providers on reimbursement for costs.

I do not believe the BGA's assertion that there has been no progress in the delivery of long-term care is correct. Despite failures and mistakes by individual providers and inadequate government regulation and reimbursement, long-term care facilities have made great advances in recent years in improving health care delivery and the quality of life for their residents.

Senator PERCY, I commend your outstanding legislative record in supporting programs for the aged. I appreciate your interest in long-term care problems in Illinois. I urge you to support such regulatory reform legislation as S. 1470, the Medicare/Medicaid Administrative and Reimbursement Reform Act which would establish much needed improvements in the medicaid program. I also urge you to examine the implementation of Public Law 92-603 by HEW in Illinois and in other States. Easing taxpayer burdens and limiting government expenditures is a worthwhile goal, but it should not be accomplished by ignoring the legitimate long-term health care needs of the elderly and handicapped.

Senator PERCY. Thank you very much.

Mr. Canaday, would you identify yourself?

**STATEMENT OF HUGH CANADAY, EXECUTIVE DIRECTOR, ILLINOIS  
COUNCIL FOR LONG-TERM CARE, CHICAGO, ILL.**

Mr. CANADAY. Certainly, Senator. I'm executive director of the Illinois Council for Long-Term Care. It is an association of proprietary facilities, approximately 10,000 beds, about 8,000 of which are in the Chicago area.

Senator PERCY. And how many different homes?

Mr. CANADAY. Fifty-two facilities.

Senator PERCY. You count a facility as one facility, not a group of five owned by one group; 52 separate facilities?

Mr. CANADAY. Fifty-two separate facilities.

Senator PERCY. And they're all proprietary?

Mr. CANADAY. All proprietary—28 in Cook County.

The Illinois council does support day care and alternative programs. We have talked with the State of Illinois, both public aid and the department on aging on these programs.

We also would support changes in some of the regulations for long-term care. I don't believe regulations are the big problem. I think a commitment is the problem. I think there must be a commitment by both the State and Federal Government to the regulations which they promulgate, and to support those regulations, both administratively and financially.

The State agency—

Senator PERCY. When you say administratively, do you mean the Federal Government, which obviously provides a lot of the money but who in our Federal system of government much prefers to have the delegations of supervision to State and local governments? Are you saying that the Federal Government should directly administer and provide the inspection service and not delegate that to the State and local governments?

Mr. CANADAY. No, sir. I am not going that far, although I would not rule that out as a possibility.

I am saying that the surveyors who do the validation surveys must be provided to the Department of Health, Education, and Welfare, that they must be funded and have an administrative responsibility.

The Illinois Council for Long-Term Care is directly opposed to both the content and manner of presentation of the news series on nursing home abuses presented by WLS-TV. We feel this series was a disgraceful distortion of fact and an irresponsible condemnation of the entire nursing home industry.

Even though the entire industry has been indicated as not being included, they only said it once during the series. There were many indications of the industry abuses.

I will not speak to individual abuses found in facilities. I have not been involved in those abuses, and I have not had any additional information to check.

Senator PERCY. How do you come to the categorical conclusion, then, that what they have presented is distorted, if you have no firsthand information about it?

Mr. CANADAY. I have no firsthand information on the abuses in the five facilities which they indicated. However, there were many misstatements and half-statements in the news releases, if I may continue.

Senator PERCY. Sure.

Mr. CANADAY. The reporters indicated the industry wants to patrol itself. The industry should patrol itself, not to the exclusion of any Federal or State agency.

In written testimony at the hearing in Chicago on July 11 of this year, the council said in writing, "Certification survey is a regulatory function, and as such, should be conducted by representatives of the State or Federal Government."

The channel 7 series indicated exactly the opposite. The only total rate quoted in the entire series was \$82.50 a day by an unidentified speaker. There was no mention of the fact that the rate paid by the department of public aid in Illinois is approximately \$19.46 a day.

Senator, if I may, I believe the 65 cents was a per-meal figure, not a per-day figure. I do not have that in my statement, and I wouldn't say for sure.

The two corrections made during the series is an indication of both the lack of knowledge of the subject being investigated and the shallowness of the investigation.

A picture of a foreign nurse who is, in fact, a U.S. citizen, shows a lack of any in-depth investigation. The quotation of a rate of \$187 per month for range of motion shows a complete lack of knowledge regarding the system being criticized.

The statement of correction is even incomprehensible when it says that \$187 figure is a total amount which can be paid per patient under the current Illinois point system. I challenge anyone to explain to me rationally what that statement means, even the correction.

The reference to 1970 is sensationalism. The BGA did not go to any legal and constitutional authority. They had various reports which they cited which indicated that conditions were much better than in 1970. They did not go to any of these agencies. They did not even bother to attend the HEW hearing which was being held the same week that they broke their story. Instead, they felt qualified to be policemen, judge, and jury, and aired their unsubstantiated allegations smearing the industry, charging bureaucratic bungling, or at least buck-passing and legislative inaction.

No one has been helped by the sensationalism. The elderly and infirm have had their privacy invaded by hidden cameras. That is their home.

Senator PERCY. Was there any objection registered by any of these homes that you know of?

Mr. CANADAY. Not to my knowledge, no. Again, I have not been in contact—

Senator PERCY. Is it an invasion of privacy when they obtain the permission of a home to come in and televise?

Mr. CANADAY. I would consider it an invasion of privacy unless they had the permission of the residents whom they filmed and who they showed on television. That is that resident's home, and I frankly do, yes, consider it an invasion of privacy.

Senator PERCY. In a proprietary area, the home is owned by the owners, of course, and the patients are there just by leave of their applications having been accepted.

On that particular point, Mr. Brunner, would you testify at this point as to what steps were taken by you and by WLS—they can speak for themselves—to obtain permission to enter the nursing homes and to do the filming?

Mr. BRUNNER. Well, Senator, there were a lot of—I really don't want to talk for WLS, because there were a lot of techniques used with the cameras, and in a sense, by the investigators, that were unique to WLS in this particular investigation, and quite frankly, they've asked us not to reveal that.

I can tell you in many instances—Ms. Klein and other lawyers in our staff have written extensive memos on the right to privacy.

Of course, we had the investigators, and many of them were lawyers themselves, research that issue quite thoroughly and they found no problem.

Senator PERCY. All right.

Mr. CANADAY. Nursing home residents, elderly persons who may soon be needing care and families of both have been frightened unreasonably by unsubstantiated allegations and innuendo. Persons needing nursing home care may refuse and have certainly postponed their entry into this portion of the health delivery system.

Conscientious employees have again been slandered and demoralized by those who do not recognize their accomplishments. These are the people providing care to 80,000 aged and infirm residents in Illinois.

This is the bottom line, the total impact on the individual needing care. The long-term care industry is open for inspection. Survey reports are public information. Cost reports and ownership information are on file with the State. Any local, State, or Federal regulatory or properly authorized investigative agency has access to any facility.

Last but of tremendous significance, every facility is open daily for visits by friends and family of the residents.

I believe in freedom of the press and would not suggest abridging that freedom. However, I do ask that this committee request the news media to act in a responsible manner and to take future findings to legally constituted authorities for objective investigation before those findings are made public.

Senator PERCY. I'm not sure I should ask them to always deal with nursing home owners and operators as objectively and fairly and on

balance as they do with politicians, but for the most part, I've found their use in politics pretty fair, pretty reasonable, and I don't have any quarrels or complaint, and I would hope that you wouldn't. I would hope that your testimony would be read by all the media and taken to heart to be sure that they do lean over backwards.

We will keep the record open in any case if BGA or WLS would want to respond to that. The record will be kept open for them to do so. [See next page.]

[A supplemental statement of Mr. Canaday follows:]

#### SUPPLEMENTAL STATEMENT OF HUGH CANADAY

On behalf of the council, I would like to submit additional comments on three issues which were raised at the committee's hearing August 30, 1978, in Chicago.

First, the council strongly supports alternatives to long-term care such as adult day care, home health services, and other programs aimed at helping people in their own homes. In cases where an individual can receive adequate services in the community, the individual should be encouraged and helped to remain in the community as long as possible. The advantages to the individual in staying near family and friends in familiar surroundings are obvious. In addition, we recognize the need for cost control at both the State and Federal level, and the need for alternatives to help control the cost of long-term care.

Second, in response to Senator Percy's question on improvement of enforcement of regulations by both the State and Federal agencies, I would like to reiterate my statement that a commitment by both the State and Federal government is required. There needs to be a clear delineation of authority and responsibility between the State and Federal agencies. Clear, reasonable, and enforceable regulations need to be developed. Finally, those charged with enforcement must be supported administratively, financially, and if necessary, by legislation.

Everyone wants alternatives to long-term care, but where is the commitment? Ten years ago the Federal Government almost destroyed home health care by stringent requirements and retroactive denials of payment under medicare. Today, adult day care is going the same way because of a lack of State funding and red-tape. Everyone wants quality care, but the Illinois reimbursement system, approved by DHEW, does not encourage quality care. Payment is tied to a median cost, so service will seek a median level. Everyone wants regulations enforced. Frequent turnover and reorganization at both the State and Federal levels, hiring freezes, salary freezes, and actual staff reductions make a good, ongoing enforcement program difficult to develop.

I would like to call particular attention to a statement which I believe was made by a BGA representative in response to Senator Percy's question regarding the primary indication they found that quality care was not being provided. The response indicated it was not so much actual abuse as a lack of attention by properly trained (or qualified) staff. This statement is much easier for the council to respond to than the previous indication of widespread patient abuse throughout the industry. The qualifications, training, and even numbers of staff are to a great extent not specified by either State or Federal regulations. Requirements for minimum licensed nursing staff in Illinois ICF's exceed Federal requirements. However, except for minimum levels of licensed nurses, key administrative staff, and some program directors, the regulations are silent. This includes licensed nursing personnel above the minimum, nurses aides, and staff for special programs. The numbers of such personnel are at the discretion of the facility and the Illinois Department of Public Health. Required training is minimal, I believe, consisting of orientation and periodic inservice.

The "cost related reimbursement system" in Illinois is based on median costs by HSA. Even the point system allowances for nursing care are based on aggregate costs using a regression formula. Given this payment system, there is no recognition of the increased cost of hiring additional staff or providing additional training except as these costs effect the median in future years.

► In summary, requirements for both numbers and training of staff are very limited. The payment system discourages, and may even prohibit, a facility from hiring additional staff or providing additional training. The State of Illinois, by its payment system, has identified an "acceptable" level of care the State will pay

for. DHEW, by approving the system, has concurred, or at least indicated the system meets Federal requirements. The industry has pointed out the danger of payment at a median rate. However, the State has determined that payment will be made at the median for an "acceptable" quality of care. If the quality of care in Illinois is not acceptable to the committee, or you find it is not acceptable to the people of Illinois, I hope you will make recommendations for changes which will correct the situation.

[The response from the Better Government Association to testimony of Hugh Canaday follows:]

#### RESPONSE OF THE BETTER GOVERNMENT ASSOCIATION

Mr. Chairman, the Better Government Association welcomes the opportunity to respond to the testimony of Mr. Hugh Canaday, executive director of the Illinois Council for Long-Term Care. Mr. Canaday expressed his concern that the BGA/WLS-TV investigation and exposé of patient abuses at nursing homes interfered with the nursing home residents' right of privacy.

The BGA has long been concerned with the plight of nursing home residents and has focused upon their problems several times during the past 10 years. On each occasion, the BGA has demonstrated an extensive concern for protecting the residents' rights of privacy. In this regard, it should be noted that:

(1) The law of privacy is intended to protect individuals, not corporations or other commercial enterprises, from unwarranted publicity concerning intimate details of private life which would be offensive to a reasonable person and are not of legitimate concern to the public. The right of privacy does not include the right of business to secrete from public scrutiny unsavory practices or violations of law.

(2) The photographs of nursing home residents which appeared in the televised reports were carefully cropped, and the eyes of the residents were blocked out, to prevent identification of the individual and preserve that person's right to privacy. The names of the residents were not used to avoid any embarrassment that might result.

(3) BGA investigators were legitimately in the nursing homes as bona fide employees of the homes. As we testified previously, of the 11 nursing homes which employed BGA investigators, only 1 conducted a background check prior to employment.

Since the findings of our nursing home investigation were aired on WLS-TV's Eyewitness News, the BGA has received scores of telephone calls and letters from viewers reacting to the exposé. Almost every response was favorable to WLS-TV's format; not a single phone call or letter was received from a nursing home resident objecting to the use of his or her photograph in the televised series of reports.

The BGA also wishes to take this opportunity to respond to two other comments of Mr. Canaday. Mr. Canaday stated that no BGA staff member was present at the HEW hearings on long-term care facilities held in Chicago in July of this year. A BGA investigator, Miss Gail Feiger, did attend those hearings. Mr. Canaday also criticized the BGA alleging that we have not cooperated with government and law enforcement officials responsible for nursing homes. BGA has and will continue to cooperate with any government or law enforcement agency interested in our findings.

Once again, we thank the chairman for affording us this opportunity to elaborate upon our previous testimony.

Senator PERCY. Mr. Waltmire, would you identify yourself, and would you pass that microphone down?

#### STATEMENT OF RICHARD WALTMIRE, ADMINISTRATOR, BETHANY TERRACE NURSING HOME, MORTON GROVE, ILL., A DIVISION OF BETHANY METHODIST HOSPITAL AND HOMES, CHICAGO, ILL.

Mr. WALTIRE. Senator Percy—

Senator PERCY. I'll ask the staff members to just hold up the 1-minute point signal.

Mr. WALTIRE. I am Richard Waltmire, administrator of Bethany Terrace Nursing Home in Morton Grove, Ill., a division of the

Bethany Methodist Hospital and Homes of Chicago. I will speak this morning strictly as an administrator representing administrators in the field.

Although we are a part of the Illinois Association of Homes for the Aged and the American Association of Homes for the Aged, and I am a member of the American College of Nursing Home Administrators, my words are my own impressions, thoughts, and they do not represent those organizations.

When the investigation by the Better Government Association started, I made a call to WLS-TV and to BGA to inquire or to find out where the investigation was going and the point that they were hoping to accomplish. One of the comments that I received was their emphasis on the point system in the State of Illinois, to show that it was impossible to provide proper care under the point reimbursement system. Through this procedure, in going into the homes, they found all these other types of problems, and that became more prominent, I think, than the emphasis on the point system.

I invited the BGA people to our home. They accepted the offer. They came out to spend a very short period of time, and if I recall the facts, they were there for probably 2½ hours and were free to go through the home. They had an enjoyable visit with a 100-year-old-plus gentleman who they just happened to meet in our corridor. He asked them to come back again for his 101st birthday, and they hoped that they would be around to enjoy it with him.

I would like to say that one of the problems, of course—and this was mentioned many times—is we're confronted with paper care instead of patient care, and the interpretations of regulations, whether they be Federal, State, joint commission, or whatever. Many people do not know the figure I had about 2 years ago. But if the nurses and personnel taking care of the residents in a nursing home were to chart and take care of everything for that patient, it would be necessary for them to make 133 entries in a nursing chart per day. That meant, Senator, that when I left my home this morning with 250 residents in it, my nurses would have to chart 32,250 entries today in order to see that the patients were properly covered with all the necessary requirements and needs that were required, as far as documentation is concerned.

I think the law of averages would say that if you missed 3,000 of those entries—which average 12 per chart—you would have minimal errors. I can see when there's any kind of a check on charts, some errors or omissions possibly can happen.

As we begin to add regulations and add to the disciplinary workings of nursing home care, I think many times the State and Federal people have forgotten about this element, as additional disciplinary care adds dollars.

When we begin to add and talk about the physical therapy people, the occupational therapy people, the speech therapy people, the theological people, discharge coordinator, nursing personnel, and so forth, that we are required to have, depending upon how and what you do with them, they mean dollars. They are not cheap dollars, and when you begin to add to these disciplines this adds to the cost of care which we are not getting back in our reimbursement.

I can only speak for myself, but I think what goes on in a nursing home has to be the philosophy of the administrator, of himself or herself, in conjunction with the board for whom they work.

In my case, I have been brought up through some very, very strict feelings concerning the nursing home work, and I will settle for nothing less than total quality care.

The State of Illinois rules and regulations, as an example, says you must have sufficient staff to handle your people. I think if we took a poll of all of us sitting around the table in this room to define the word "sufficient," we would probably get all kinds of different answers.

Having come to the State of Illinois some 4 years ago, serving a number of years in Wisconsin, and having knowledge of other States, I know the definition of care is defined as so many nursing hours per patient per day. That can vary, of course, depending on the kinds and levels of care that you have. But in the State of Illinois, we have no such definition. Only "sufficient."

So, one can be criticized and another one can be praised by the number of personnel they have on board. I think these are some of the things that present us with a great problem.

When we also think about the problems that can exist in homes, we have lost track of the fact that the doctors are never pressed by any of the investigations that go on to know what the various problems we have in getting them to care for the residents. I think it is very, very important, to enforce visits each 30 days for the first 90 days and each 60 days thereafter, or as it's required, and some of the doctors do not care for these regulations.

In our case, if a doctor does not take care of the residents properly, we ask the family to change physicians or ask for the discharge of the resident. They have their choice of physicians, and we enforce that.

We have over 80 doctors that come to our particular facility, and I'm sure that other facilities have the same.

These are some of the problems we face. We have not heard about any deficiencies that occur in the homes because the doctors have not come in. What has the government done with the doctors? Not a whole lot. If anything, their peers have done very little, to our knowledge, to enforce that. The doctors will say, "Fine. Get another physician."

We think about the work of the utilization review procedure in the homes. A utilization review committee consists of three physicians and personnel within your home. We pay these physicians to do this work. They are physicians who are not employees of our home. We then have the medicaid people come in from the public aid offices and sit down, go through and check on your chart work, score your residents points, and assess your care points for you. The utilization review committee have spent hundreds of dollars to determine that the patient is skilled care or intermediate care. You then have a clerical individual coming from public aid, with whatever their skills may be, and some are not totally skilled medically, and will assess the individual at a skilled or intermediate level. Their point assessment can totally reverse the utilization review committee. So why do we pay the physicians, and why do we pay the personnel to sit and go through utilization review when

somebody else comes in and changes your level of care so your cost of reimbursement is affected?

This can go on and on. We are aware that the point system is designed to keep people sick, and this is also true in our facility. We are totally against that. We feel that the patient should be up and about and constantly in some activity or work, receiving the various kinds of medical, social, and spiritual care, as is needed for that individual.

We like to feel that the individual is a person that we want to be totally involved with, regardless of who's paying their bill. We know what's happening to them, and this cannot be done in a lot of the homes that are strictly getting their reimbursement from title XIX. Governmental agencies reimburse us for paper care but have not yet found the formula to reimburse us for quality geriatric nursing home care.

Thank you, Senator, for this opportunity to testify. If I can be of further help to you and your committee, please do not hesitate to ask. I will offer my time and services.

Senator PERCY. Thank you very much.

I would like to just ask you to say a little bit more about your own home, Bethany Terrace Nursing Home. I happen to know it to be a fine home.

Could you tell us the size of the home, how many residents you have there, what proportion of them are on public aid, and what proportion are privately financed?

Mr. WALTMIRE. Senator, our home is licensed for 265 people. We have tricensure. Twelve are of residential care and the other license is divided into intermediate and skilled care.

We consider ourselves full with 250 because of private rooms, isolation rooms, and the other necessity for rooms. In that figure, we have 22.3 percent of our residents on public aid. We also have approximately 102 people who are on private or life-time contracts, which we are receiving \$100 or \$200 a month. The rest of the people are on total private pay arrangements. So we have close to, I think this morning or yesterday, 52 people receiving public aid. This means in our home, we must underwrite close to \$24 a day of their cost, and that comes to \$35,000 per month, or \$420,000 per year.

Senator PERCY. Is full overhead allocated?

Mr. WALTMIRE. That's right.

Senator PERCY. Nonrecurring expenses. You still have to, then, subsidize?

Mr. WALTMIRE. Yes, sir.

Senator PERCY. The allowance would not be adequate?

Mr. WALTMIRE. That's correct, sir. Yes, Senator.

Senator PERCY. You could not run a home of the same standard if 100 percent of your patients were public aid, then, could you?

Mr. WALTMIRE. Not in the way—not in what we feel is our intent to provide the kind of care we feel a person should be entitled to.

Senator PERCY. Were you invited by this committee to testify, or did you volunteer to testify?

Mr. WALTMIRE. I was invited to come, Senator.

Senator PERCY. You were invited because we want to have a balanced testimony. We knew of the outstanding work you've done, and certainly, it's our intention to see that both sides of the story are told.

Mr. WALTIRE. However you got my name, I can't tell you.

Senator PERCY. Well, the reputation goes ahead of you.

Mr. WALTIRE. Thank you, Senator.

Senator PERCY. I have received an anonymous note which I am reluctant and will not put in the record unless someone identifies and signs it. Whoever wrote this note, you'll recognize it. If you care to come up and sign it either now or later, I'd be happy to insert it in the record.

Our next witness is James Scheibly, administrator of the Champaign County Nursing Home, Urbana, Ill.

Mr. Scheibly, you are welcome.

**STATEMENT OF JAMES A. SCHEIBLY, ADMINISTRATOR,  
CHAMPAIGN COUNTY NURSING HOME, URBANA, ILL.**

Mr. SCHEIBLY. Senator Percy, the Champaign County Nursing Home is owned and operated by the county of Champaign as a non-profit nursing home. We have 269 beds, in which we incorporate skilled care, intermediate care, day care, home health and sheltered care services, all under one roof.

I would like to address the subject of alternatives to long-term care for a few minutes.

Adult day care and home health services do not refer to a single service but to a broad spectrum of services designed for the elderly with varying levels of need.

In order to maintain the elderly in the community and home environment as long as possible, we must have a philosophy and commitment to a full spectrum of therapeutic, rehabilitative and social support services. This involves our current available resources, such as acute care and long-term care—we don't feel we can do without these—home health and senior citizens recreation and nutrition programs.

At the present time, there are omissions in these available services which prevent the elderly from remaining in their homes longer. Home health services need to be expanded to include additional homemakers, home maintenance services, and nutrition counseling, to mention only three.

Providing adult day care for those who need it in a setting that provides health services and social stimulation would fill a gap that now exists, and I feel would be a step in maintaining the elderly in a community and home longer.

I won't go into all of the problems of the elderly, because I'm afraid everybody here I know is very well aware of them.

At Champaign County Nursing Home, we offer multidisciplinary services in both the nursing home and adult day care and the home health services. To prevent inappropriate institutionalization, we must identify the components comprising the continuum of care and establish new services as required.

Once the clients' needs are assessed, proper and appropriate services can be provided by one or a combination of major components.

When there are gaps in this continuum, we often see placement of elderly in the more extensive level of care because of the erroneous assumption that skilled and highly technical health services can only be provided in an institution or clinical setting.

Also, another reason why inappropriate placement of elderly in long-term care facilities occurs is because their needs fluctuate over the entire range of services, and where the needs requiring the highest skill is offered, no matter what percentage of time this service is needed, is where the client is placed and sometimes left, sometimes left forever.

Because of this changing of clients' needs, a continuous evaluation must be made to insure that he is receiving proper service at the appropriate level. Utilization review and discharge planning in acute and long-term care facilities is a step in the right direction. However, discharge planning and utilization review cannot be effective if there is not a place to be discharged to, the home environment, or if a client cannot receive the supportive services needed to keep him in his home.

Day care and home health become a valuable component in the continuum of care when the program offers a full range of services, whether for personal care or a highly skilled and technical service. All too often, established clinical and institutional facilities and service agencies themselves determine where and what services elderly are provided, when it should be the clients' and his physicians' choice of where and what services are needed and for how long.

Adult day care and home health services should be made available equally to all elderly, regardless of whether they live in the country or the city. Cost effectiveness of these programs as opposed to institutional health care has been documented by many throughout the United States.

Although many still dispute the cost effectiveness, we can state that it does not cost \$200 a day for home health care, and it doesn't cost \$40 a day for day care.

Senator PERCY. Did you hear testimony given today that home health care might be more expensive than institutionalized care? I suppose they're not talking isolated cases, but they're talking in generalities, to which you objected?

Mr. SCHEIBLY. It could be, over the long run, it could be more expensive. If it is, then the assessment has not been made to the patient on what types of services that was needed.

I'm not talking about going in and seeing this client for the 100 visits that's allowable so that you can collect as much as you possibly can. I'm talking about providing the client the services that are needed.

Senator PERCY. And the variety of cases, infinite variety, some of which might need nothing but meals-on-wheels, some that might require a good deal of home care. But averaging it out, as you say, in your judgment, the cost is less than the cost would be for institutionalizing them in a facility such as you maintain?

Mr. SCHEIBLY. That's right.

Senator PERCY. That's my conclusion, also. Otherwise, I wouldn't be pushing this end of it so much. But I have heard testimony to the contrary, and I wanted your expert advice, not my uneducated guesses.

Mr. SCHEIBLY. The elderly who have received these modes of care speak long and convincingly and unashamed of their bias in favor of these methods of health care delivery.

In conclusion, it has been proven that day care and home health for the elderly is a workable, cost-effective concept preferred by the elderly and their families to institutionalization.

I'd ask you at this time to urge your committee and the Senate to establish a national task force on adult day care with the specific objectives of developing a national policy on adult day care and recommending to HEW and the Congress appropriate funding sources and levels, guidelines for standards, assessment and evaluation.

We must do this now in order to insure a comprehensive, yet cost-effective health delivery system for the elderly that can be free of the abuses which some of the long-term care industry has been plagued.

Title XX funding we know is available for services of many things, but the health component is limited. We feel that probably the only way that we can go with this is with the medicare or medicaid component for reimbursement.

Senator PERCY. As you know, I recently went down and visited your jail in Champaign, and when I came out I classified it as one of the worst jails I've ever been in in my life. It was a despicable place to put human beings and a disgrace to an enlightened county such as Champaign.

Your own nursing home is, I think, for a county nursing home, one of the finer ones that we have been in. Its facilities are clean and excellently maintained. You have a fine staff, and your testimony is evidence of that.

Did you volunteer to testify today?

Mr. SCHEIBLY. No, sir. I was requested to testify.

Senator PERCY. Requested to testify by the Senate Special Committee on Aging?

Mr. SCHEIBLY. Yes, sir.

Senator PERCY. And the presumed purpose, I imagine, would be to give public testimony to the fact that both proprietary and public, it is possible to maintain excellent facilities and provide humane, decent loving care.

Mr. SCHEIBLY. Senator, if I could just say one more thing in defense of the public officials in Champaign County, the decision was made a good number of years back to either go with the jail or a new nursing home, and the public officials voted to build the county nursing home first, then the jail.

Senator PERCY. My only message to my friends in Champaign and Urbana with whom I've been arguing about this is that if you're ever going to rehabilitate criminals, if you want to put criminals into a facility that will make them angry at society when they come out, it's that jail. But if it's a choice due to limited resources, I agree they put their money in the right place. But the cliché that "We're not going to build a Holiday Inn for our criminals down here" is really to misunderstand the nature of law enforcement and what is necessary, because that jail would turn beginning criminals into hardened criminals by the time they left.

I think your nursing home gives everyone who comes into it the impression "society really cares about me." We really appreciate your testimony very much.

[The prepared statement of Mr. Scheibly follows:]

PREPARED STATEMENT OF JAMES A. SCHEIBLY

Adult day care and home health services does not refer to a single service but to a broad spectrum of services designed for the elderly with varying levels of need.

In order to maintain elderly in the community and home environment as long as possible, we must have a philosophy and commitment to a full spectrum of therapeutic, rehabilitative, and social support services. This involves our current available resources such as acute care, long-term care, home health, and senior citizens recreation and nutrition programs. There are omissions in these available services which prevent elderly from remaining in their homes longer. Home health services need to be expanded to include additional homemakers, home maintenance services, and nutrition counseling, to mention only three. Providing adult day care for those who need it in a setting that offers health services and social stimulation would fill a gap that now exists and I feel would be a step in maintaining elderly in the community and home longer.

In order to meet a client's individual needs, we should think of a multidisciplinary and multidimensional approach. Problems of the aged can be broken into four general divisions which are: Socio cultural, physiological, economics, and psychological. Some of the elements in each of these general categories would be as follows:

**Sociocultural:** Diminished social role, communication breakdown, isolation and rejection, dependence on others.

**Physiological:** Multiple chronic diseases, degenerative process, sensory deprivation, increase risk of injury, nutritional deficiencies.

**Economics:** Reduced income, increased expenses (medical care), inadequate retirement benefits (pensions and social security).

**Psychological:** Cognitive and/or emotional disorders, organic brain syndrome, presenile and senile dementias.

I included the above paragraphs in order to emphasize the multiple problems elderly have. You cannot focus upon one problem and hope to be successful in treatment without dealing with and being aware of other participating factors. In order to provide services that meet individual needs, I have attempted to diagram the procedure used in identifying the problems:

Person → reason he is referred → identify and assessment of contributory problems → develop multidisciplinary plan → perform care/service → evaluation → person.

With proper identification of a client's problem and appropriate treatment levels (whether it is in day care or home health) the over treatment sometimes seen in acute and long-term care can be avoided.

The following is a list of multidisciplinary services that are being provided by Champaign County Nursing Home in both adult day care and home health services: Nursing, occupational therapy, physical therapy, nutrition, social services, social rehabilitation, dental services and speech therapy. For day care there is also beauty and barber shops and organized activities. The home health services operate continuous health screening clinics in nine sites in Champaign County.

To prevent inappropriate institutionalization, we must identify the components comprising a comprehensive continuum of care and establish new services as required. Once the client's needs are assessed, proper and appropriate services can be provided by one or a combination of major components. When there are gaps in this continuum we often see placement of elderly in the more extensive level of care because of the erroneous assumption that skilled and highly technical health services can only be provided in an institutional or clinical environment. Also, another reason why inappropriate placement of elderly in long-term care facilities occurs is because their needs fluctuate over the entire range of services and where the need requiring the highest skill is offered (no matter what percentage of time this service is needed) is where the client is placed and sometimes left. Because of this changing of client's needs, a continuous evaluation must be made to insure that he is receiving proper services at the appropriate level. Utilization review and discharge planning in acute and long-term care facilities is a step in the right direction. However, discharge planning and utilization review cannot be effective if there is not a place to be discharged to (home environment) or if a client cannot receive the supportive services needed to keep him in his home. Day care and home health become a valuable component in the continuum of care when the program offers a full range of services whether for personal care or a highly skilled and technical service. All too often established clinical and institutional facilities and service agencies themselves determine where and what services elderly are provided, when it should be the client's and his physician's choice of where and what services are needed and for how long. The following diagram represents a continuum of care giving the client, his family and physician alter-

natives to choose from for various levels of care. It also demonstrates the flexibility in utilizing the various components individually or simultaneously for varying periods of time.

When providing a service for the elderly we think of the older client who is living at home with their spouse or adult children. Although adult day care has functioned as an alternative to nursing home in-patient care for almost two decades in England, this community-based mode of long-term care for the elderly has just come under study in the United States. Much of the cause for this slow growth can be attributed to consequences of medicaid and medicare, which has long favored payment only for institutional care. But health care costs are spiraling, particularly institutional cost. The Social Security Amendments of 1972 (Public Law 92-6-3, section 222) specified that adult day care would be one alternative form of health care delivery modes considered. Champaign County Nursing Home currently operates a viable adult day care program serving 20-22 intermediate and skilled level of care participants daily. It has proven to be a satisfying and economical alternative for some individuals to total institutionalization. From its inception to the present, the largest problem has been no public funds to cover the cost of day care. If public funds were available we are confident the number of participants we would serve would be limited only by the physical limitations of space available in our building.

Education and counseling of family members and clients are of prime importance in order to maintain the elderly in their homes. Not only in how to care for their older adult in relation to his specific condition during the hours he is home, but also to give moral support from trained professionals. Screening clinics for day care/home health will be effective treatment for some conditions (hypertension, dental, glaucoma, diabetes). Many elderly are reluctant to spend money for medical care and routine physicals until a health crisis situation occurs.

Adult day care and home health services should be made available equally to all the elderly regardless of whether they live in the country or in the city. Cost effectiveness of these programs as opposed to institutional health care has been documented by many throughout the United States. Although many still dispute the cost effectiveness, we can state that it does not cost \$200 a day for home health or \$40 a day for day care. The elderly who have received these modes of care speak long and convincingly and unashamedly of their bias in favor of these methods of health care delivery.

In conclusion it has been proven that day care and home health for the elderly is a workable, cost effective concept preferred by the elderly and their families to institutionalization. I would ask you at this time to urge your committee and the Senate to establish a National Task Force on Adult Day Care with the specific objectives of developing a national policy on adult day care and recommending to HEW and Congress appropriate funding sources and levels, guidelines for standards, assessment, and evaluation. We must do this now in order to insure a comprehensive yet cost effective alternate health delivery system for the elderly that can be free of the abuses which some of the long-term care industry has been plagued. Title XX funding offers many needed services for the elderly but the health component has been neglected. The appropriate funding source for day care and home health might be title XIX of the medicaid program.

Mr. WALTMIRE. Senator.

Senator PERCY. Yes.

Mr. WALTMIRE. I wonder if I could add a comment to his concerning the home health care situation.

A couple of years ago, in Washington, before Congressman Claude Pepper and his committee, the home health care issue was brought about as an alternative to the kind of care that we provide in our facilities.

You bring up the possibility of it costing more with the other contradictory statements about it being less costly.

I think what will happen, and this is my own personal feeling, is that as we begin to find the people who need home health care, we're also going to find many of those particular people needing care that we provide in our facilities. We, in turn, send many of our people home, so I think what we're going to find in developing home health

care, that there is going to be a lot more people found who may need institutional care in our kind of facility, and that may be where you'll add to the cost.

Senator PERCY. I'd like to give, once again, a chance for the person who sent this anonymous note up to sign it.

Mr. HANNON. I'll sign it.

Senator PERCY. You will sign it. OK. Fine. Thank you.

I'll read it into the record, then, so we won't have any curiosity about it. The note is somewhat critical of the Special Committee on Aging, of the BGA, and WLS television, so I want to be sure we don't evade that critical note. I'll ask you if at the end of the hearing if you'd want to modify or amend it in any way, put it on the record.

Our next witness is Suzanne Weiss, director of Accom-O-Day Care Center in Chicago.

**STATEMENT BY SUZANNE WEISS, DIRECTOR, ACCOM-O-DAY CARE CENTER, CHICAGO, ILL.**

Ms. WEISS. Thank you. Senator Percy, Mr. Grisham, and Mr. Lewis, I would like to precede my remarks with a request. I have carefully prepared my presentation to include no more than 10 minutes. I hope that since Accom-O-Day is one of the alternative care systems being discussed today, perhaps I could respectfully request that I be able to finish it in its entirety. It is my feeling that it is of extreme importance to the immediate—

Senator PERCY. Permission granted.

Ms. WEISS. OK. Thank you.

Senator PERCY. I'll take it out of my 5 minutes for questions.

Ms. WEISS. You might have more than 5 minutes of questions, I hope.

It is with extreme pleasure that I find myself able to formally present to you an existing, successful and heretofore unrecognized and authorized entity which can and does function as one alternative to institutional placement for a segment of the elderly population. Accom-O-Day Care Center functions in many capacities as an option to home care, institutional care, or to no care. The clientele are those who are marginally able or unable to maintain themselves in the community. With day service, maintenance in the community becomes viable, no longer marginal—in fact, normal.

Stimulation, activity, minimal nursing care, and good nutrition constitute the basic needs of all marginal elderly. These needs can be met in a day care setting such as Accom-O-Day.

Specifically, I would like to address myself in the next few minutes to two main points regarding Accom-O-Day Care Center. The first pertains to its inception, struggle to exist, quality of care, and present threats to its existence; the second provides evidence and rationale regarding the expenditures made to maintain elderly in the home and delineates specific services we render. Attached to this testimony is additional information regarding program components, logistics of staffing, family testimonies regarding care and need, as well as professional input from local coordinating service agencies.<sup>1</sup>

<sup>1</sup> Retained in committee files.

Accom-O-Day was opened 2 years and 10 months ago with a small amount of financial backing from personal savings. A full staff was recruited from the professional wives of the owners, I might add at no salary. Clientele came slowly and so did the promised funding from the Federal Government. For over 2½ years we have applied, reapplied, and pleaded at the State level for funding for day services. A tremendous capital outlay accrued, clientele numbers, due to client's financial status—that is social security—kept the numbers consistently too low to cover quality care costs. Hence, quality care was maintained, financial loss incurred.

On July 14, 1978, we no longer could sustain further financial losses. Our pleas, contacts, conversations, and proposals for funding to the State agencies produced no success. We announced to our members and associating agencies that we would close our doors on July 28.

Within 3 days the news media, CBS, Sun Times, Tribune, Learner papers, prominent columnists and commentators were behind us—all through the concerted efforts of approximately 20 members and their families and a dedicated staff. Local agencies were willing to carry away our garbage which we could no longer pay to remove, or to march to Springfield to picket our lack of funding. Within 4 days Springfield called us, requesting that we come down to explain our needs. Within 5 days we were able to safely say that the department on aging was committing itself to funding 55 clients per day who would attend Accom-O-Day.

The department on aging and its staff are to be commended upon the remarkable abilities and concern they evidenced during our negotiations and problem-solving sessions. They were extremely capable, helpful, and made every effort to enable us to remain open.

Until yesterday, it appeared they were successful. Unfortunately, the Illinois Department of Public Aid yesterday amended their rules and procedures. Originally, 75 percent of the costs of day care were to come from the Federal Government, 25 percent must come from local donors to supply the States with the necessary 100 percent for reimbursement.

The entire concept of donor matching moneys has been a constant threat to Accom-O-Day's existence, but most crucial of all, yesterday, the Illinois Department of Public Aid instituted an up-front donor system which requires not only the local donor pledge from a 1-year contract, but moneys in advance of instituting the contract.

It is my contention that this particular system of funding is against the basic nature of human dignity and is based upon discrimination against the free enterprise establishment.

Since as a for-profit business we cannot legally underwrite ourselves as a donor, and most likely will not be able to arrange and establish a donor situation which is not or does not appear surreptitious, we are automatically written out of the funding mechanism.

The type of funding system existing today breeds a fertile ground for inept, dishonest business, a repeat scenario of what a large number of representatives of the Government are striving to prevent.

Most importantly, it negates, even denies—the fact that the free enterprise system is still the most cost efficient, service producing, highest quality controlled system in America. Accom-O-Day has proven this.

During negotiations to provide a particular nonprofit organization with day services, this was highlighted. Accom-O-Day offered to provide this agency, which by the way now has funds from the department on aging, with more services, of better quality, at less than two-thirds the cost which it receives from the State.

This agency proceeded to add to our proposed costs the additional unnecessary supervisory costs, intake costs and social work costs which we already provided, by adding staff to their agency to oversee our providership.

The unnecessary addition brought their total costs to much more than could be afforded, hence negotiations ceased.

This organization, by virtue of being nonprofit, then funded itself for the 25-percent matching, received DOA 75-percent matching funds and received the same unit price we would be receiving for less service than we would be providing.

Perhaps we should begin to look into the practices and regulations and requirements for funding and providership which the Illinois Department of Public Aid is establishing and requiring of the provider before we can really begin to question the provider and the provider status.

In my case, as an originator of day care in the Chicago area and one who has fought all odds in order to remain open, to maintain low cost to the client, and above all, to maintain quality care, I stand ready to close our doors, rather than submit to the degrading process of convincing private persons or foundations to fund what rightfully is the responsibility of the State to fund.

Very few programs of day care will come into existence. Very few survive, will survive for long periods of time, and only a handful will prove cost efficient if run on smaller scales than the approximate numbers we have established.

You speak of incentives for quality care. Incentives to quality care in the form of alternative care are being choked now by the funding system. Funding is effective in the nonprofit system through beefed up budgets. Dedication, such as evidenced through continual efforts, incurred debts, and in specific cases such as mine, a person who has worked 3 years with no salary and long hours, will not be forthcoming in a nonprofit organization which does not receive its budget.

I would like to personally volunteer my services at this point, since Accom-O-Day can no longer find itself financially able to remain open after this month unless we receive a fair reimbursement system, to aid your committee in developing a successful method of utilizing the Federal moneys allocated for alternative care. If I've worked for 3 years without salary in an ineffective method, I'd much rather do it in an effective method.

Incentive to provide health care for the elderly and community contacts is choked even before its true assessment can come to fruition.

Incentive to run this type of demanding program comes from pay. In the nonprofit organization, pay is in the form of salaries, fringe benefits, and heavy staffing, thereby requiring less of each individual.

In the free enterprise system, pay comes after the quality is produced, and the price is determined not by the numbers of overstaffing or salaries incurred but by the quality and quantity of service provided.

The competitive free enterprise wins except in the eyes of the Illinois Department of Public Aid. The ultimate losers, of course, are the elderly persons who no longer have an alternative quality care system such as Accom-O-Day to attend.

What happens to these elderly? Do they accept either inadequate or more expensive care, or perhaps premature institutionalization? What happens to a facility such as Accom-O-Day which provides quality care through a total staff involvement if it must divert some staff energies to finding a donor? Either their costs increase or quality suffers.

How is one small budget to cope with this frustrating dilemma?

Let us turn now to the services rendered, their costs and their intangible value. Accom-O-Day offers the following services.

Social rehabilitation, including reality orientation and remotivation, a full activity program, medical services provided by a nurse, speech therapy, physical therapy upon request, social worker consultations; one main meal and two snacks, plus transportation. The members may choose to attend on a full unit basis of 8 hours or a one-half unit basis of 4 hours.

Dr. William Weissert, research fellow at the National Center for Health Services Research with the U.S. Public Health Service, has shown that day care is less expensive than institutional placement, especially the type offered by Accom-O-Day, since day care is an intermittent form of care which calls upon the family to respond and supply a large portion of the care expense of the elderly.

On a yearly basis, considering part-time attendance as the main form of attendance, Weissert was able to ascertain that day services saved 37 percent to 60 percent of the cost of institutional placement. It will be interesting to note that in this particular study, cost efficiency was not at its highest since the average number of clients per day was 28. At Accom-O-Day we hope to be even more cost efficient by caring for 55 clients per day.

The most important aspects of day care are the intangibles, the nonquantifiable, yet, if we scientifically measured the responses of the families who place their elderly at Accom-O-Day, or if we observe the changes in self esteem, self image, and dignity of the elderly members we would find that we certainly cannot place a monetary value upon this kind of service. The extended family will certainly find support in day service. The needs of the elderly must be met in human, family-supported, caring setting.

I thank you for the opportunity to speak.

Senator PERCY. Suzanne, I would like to say to you I have not been personally familiar with your work. Your gracious and generous offer of voluntary assistance in support of this committee is very much appreciated. I will consult with my colleagues on the committee, but on behalf of my current consultations with both minority and majority staffs, we readily accept your offer and invitation to come to the area where we really need assistance and help.

I will direct the staff to see whether we can find some consulting money so that such a gratuitous offer doesn't have to be entirely something that you can deduct from your income tax, but have nothing to add to it.

Ms. WEISS. I will be available with more time after December.

Senator PERCY. Thank you. Thank you very much.

Our final witness is Dean Jost, I'm particularly interested in having you testify, Mr. Jost, because of the work of the Uptown Legal Services here in Chicago.

**STATEMENT OF DEAN TIMOTHY JOST, PROJECT DIRECTOR, LEGAL SERVICES FOR THE MENTALLY DISABLED OF UPTOWN, UPTOWN LEGAL SERVICES, CHICAGO, ILL.**

Mr. JOST. Thank you, Senator.

My name is Dean Timothy Jost, and I'm an attorney and project director of Legal Services for the Mentally Disabled of Uptown. Our project is a project to give legal services to people in nursing homes in the uptown area of Chicago. We are funded by the American Bar Association and by the Legal Assistance Foundation of Chicago.

We have been in existence for nearly 2 years, and during that time, I think we've seen over 400 nursing clients, many of whom are nursing home residents.

The U.S. Government is the largest single purchaser of nursing home services in the United States. The Congressional Budget Office estimates that in 1975, the United States spent \$5.2 billion on long-term care. This expenditure represented 40 to 45 percent of the market.

As other third-party payors provided only a small portion of the total expenditures for nursing home care, the U.S. Government is the only single consumer with a significant ability to determine the quality of the product offered by the long-term care industry in the United States.

The U.S. Government has, unfortunately, sadly neglected and abused its opportunities to shape the quality of long-term care.

Most of the money which the United States pays for long-term care is funneled through the medicaid and medicare programs. The United States plays two major roles in governing the medicaid program which impact on quality of care.

First, it provides a significant portion of the money which is spent on long-term care by the State, Federal medicaid programs. Second, it provides standards for quality of care which long-term care facilities which participate in the medicaid program must meet.

The Federal Government has missed significant opportunities both in the long-term care reimbursement and certification areas for improving quality of care.

At this point, the primary qualification for long-term care reimbursement established by the Federal Government is that the reimbursement must be related in some way to nursing home costs.

Although the Department of Health, Education, and Welfare allows States to provide quality of care incentives in their reimbursement formulas, they are not required, and most States do not have them. The primary goal in most State reimbursement plans, including that of Illinois, is to spend as little money as possible on nursing home care.

It is good, plain, commonsense that a consumer should pay more for good quality care, less for poor quality care, yet in some States, such as Illinois, the long-term care reimbursement so ruthlessly

emphasizes the provision of cheap care that it makes the provision of quality care very difficult, if not impossible.

The Federal Government needs legislation requiring States which participate in the medicaid program to tie reimbursement to quality of care. It is shameful and foolish that though every State in the Union is required to change its long-term care reimbursement system to provide for cost related reimbursement as of January 1, 1978, the Federal Government did nothing to require quality of care to be recognized in these reimbursement systems, and indeed, did not even provide a model reimbursement system for the States to look at in redesigning their systems.

The Federal Government should also redesign its current recertification standards for long-term care. At this point, the United States, through HEW, comprehensively defines what intermediate and skilled care facilities must look like to participate in title XVIII and title XIX programs.

States are required to inspect to insure that the facilities meet these certification standards to participate in the medicaid program, and the States are reimbursed 100 percent for their certification inspection costs.

Unfortunately, the certification standards provided by the Federal Government are woefully inadequate to define quality of care. Although in some areas, as has been said earlier, such as fire safety and access for the handicapped, the standards are fairly good, on the whole, they focus far too much on physical plant and programs and not on the actual care given the residents.

It is very unlikely that in a defense procurement program the United States would determine quality of a product by only looking at the tools and the manufacturing process used to produce the product, but this is essentially what the Federal Government has done with long-term care.

The Federal Government needs to implement a resident outcome assessment system such as the QES developed by Illinois or the PACE system which the U.S. Government is working on. It needs to require specific staffing ratios for nursing home staff and not the standard referred to earlier of sufficient staff, with State or local inspectors determining what that means.

The Federal Government also perhaps needs to provide minimum wages for the nursing home industry, as I believe it does for other industries which contract with the Federal Government.

I talked to a friend the other day who said that she was working in a nursing home where there was a very dedicated and qualified aide who had been working there for 3 years, and until recently was earning only \$2.60 an hour.

A certification system needs to be developed which would make it possible to rank homes by quality of care so the private consumer market could decide on what care it wanted.

Certification standards should recognize and protect residents' rights. Although the rights of residents currently are recognized in the HEW regulations, they have not been enacted into law. Some of the rights already provided need to be strengthened.

Nursing home residents need the right not to be transferred from a nursing home without appropriate notice and time for a hearing.

Residents and their representatives need guaranteed rights of access to their own records in the nursing homes. Privacy of mail and personal property within nursing homes needs to be protected.

Nursing home advocates must be guaranteed access to nursing home residents. Although the Federal Government has funded a nursing home ombudsman program, there has been no guarantee that these ombudsmen will have access to the homes.

Further, a private right of action needs to be provided for nursing home residents to enforce their rights.

Finally, the Federal Government needs to assist States in enforcement of certification standards and to require States to have decertification procedures so that the condition presented earlier where the State of Illinois has not decertified any home for an entire year could not exist.

The Federal Government is pouring billions of dollars a year into long-term care with total disregard for what its money is buying. It is high time that we start using this purchasing power creatively to provide the best quality of care for elderly and disabled American citizens. This will undoubtedly require new Federal legislation which will require your efforts.

I hope and trust that you will take this charge seriously and that the time and energy put into these hearings will not have been wasted. Thank you.

Senator PERCY. Thank you very much, Mr. Jost. I appreciate that.

I know that Mr. Canaday and Mr. May have testified to their feelings about the bias that might exist in the BGA and channel 7 investigation. Would any of the others of you care to question or testify as to the remarks that you heard from the first panel? What are your reactions to the charges that they made?

Also, do any of you care to comment on where the fault lies for conditions such as those described by the BGA investigation?

Mr. CANADAY. Senator Percy.

Senator PERCY. Mr. Canaday.

Mr. CANADAY. If conditions do exist, they lie directly with the facility.

Senator PERCY. They are what?

VOICES. Can't hear.

Senator PERCY. Yes, if you'd use the microphone, please.

Mr. CANADAY. If conditions exist which are as bad as the BGA indicates, the responsibility lies directly with that nursing facility and the owner of that facility.

Senator PERCY. Yes.

Mr. CANADAY. That has to be primary responsibility.

Senator PERCY. I agree with you. Primary responsibility. He operates under license. He goes into a business. He pledges to do certain things. He's obviously not doing them.

Where is the next responsibility, then, however, assuming that you wouldn't need armies or police departments if the world was filled with angels, and we're not angels in this regard. We're dealing with human beings, profit incentive, and the proprietary area is an incentive which as a businessman I would understand and expect.

I think it happens to be the best way to provide a lot of goods and services, but who has the primary responsibility beyond that, then, if there is abuse?

Mr. JOST. Senator Percy, I'd like to comment on that.

I think there are four places one has to look for responsibility. I think I probably commented today on Federal Government's responsibility because I understand that is where you have the greatest power to bring about change.

Second, I think that from my experience, the attitude of the nursing home administrator is probably one of the highest determinants of the quality of care that people in the home receive. I would say that some administrators do not care about quality, other administrators care about quality but feel very frustrated and don't know how to create it, and other administrators break their backs against all odds to really provide quality care.

I think my experience would witness to the fact that a lot of what the BGA identified is present at some homes, although certainly not in others.

Third, I think that a lot of the responsibility lies with the State governments who have not gotten their act together, to provide sufficient funding for nursing homes, and also to provide a unified effort to govern licensing and certification and make sure that is done effectively—that where abuses are discovered that they are dealt with.

I think another thing which we have to recognize, though, is that in the United States there is not the same emphasis on or regard for older people as exists in many other countries. I think that for most people, a nurses' aide job is not an honored profession that they are happy to tell their friends about and feel respected for. I think that's partially true because of the poor pay, and I think it's also partially true because it's not a profession that's looked up to, and I think a lot of things have to be done with the attitudes of Americans.

Senator PERCY. Mr. Jost, for your information, with the strong support of Senators Church, Domenici, Percy, and others, the present Senate version, that's presently in conference, of the Older Americans Act, would now authorize nursing home access to ombudsmen and strengthen the programs in other ways, following the lines of some of these suggestions that you've made.

The House version also has those same strengthening provisions that will come out of conference, so I appreciate your comments on them.

Mr. JOST. On my final point, I'd just like to make one further comment, and that is I was somewhat puzzled as to being identified here as a member of the provider panel, and I think one of the things it witnesses to is that there probably are not enough consumer groups working with nursing homes in Chicago to get together an entire panel, and I think that until residents and their relatives and people in the resident nursing home care get together enough so that there are groups which will monitor long-term care on a long-term basis, not on a one-shot basis, that there won't be changes.

Senator PERCY. HEW is now struggling with revised revisions in the regulations for nursing homes. The major thrust is to improve quality provided in long-term care facilities.

How do you, in your judgment, insure quality, and can quality be measured? Any of you care to comment? Ms. Weiss?

Ms. WEISS. Thank you.

Well, I think that quality is nonquantifiable. I really feel that all of the paper work that we might collect will not really tell us if quality was instilled into the actual performing of an act, in care of a person.

Certain numbers of times may be charted, but what actually happened in the interaction is very difficult to ascertain, and I can testify from my own personal experience in the last 3 years that when you're doing it on a fairly individualized basis such as in day care, where you've got a 1 to 7 maximum staff to client ratio and you're in a noninstitutional setting, the quality, there is an element of commitment and involvement simply by virtue of the fact of proximity over time of a staff person with these seven people, that if you were to observe this, you'd be able to see but not really measure, and I think that those are things, those are intangibles that we're trying to quantify and we really can't.

Senator PERCY. Ms. Weiss, have you found that your day care program has kept elderly people from being unnecessarily institutionalized? How would you describe your operation as to its cost effectiveness?

Ms. WEISS. Those are two parts, and I want to separate them out in my mind.

The first point—would you repeat that again?

Senator PERCY. The first question is simply, in your program, have you seen evidence that you are able to keep people from being institutionalized, and then at what cost? Is it cost effective?

Ms. WEISS. OK. Attached to the documents which I've given you are personal letters from many of the families who have stated, point blank:

Because of being able to attend Accom-O-Day, I was not required to place my mother prematurely.

or—

My father now lives at home and can work in his garden on the weekends whereas before, we had considered nursing home placement simply because we could not provide the 24-hour-a-day care. We needed respites for some period of the day.

In terms of cost efficiency, at this point, the way Accom-O-Day is running, it has been a financial loss to us.

What we have projected for the 55 clients per day, had we been able to legally obtain a donor to come up with the 25 percent matching, then we feel that we would have been extremely cost effective. We would have been able to provide 9 hours of service, including transportation, one meal, two snacks, a nurse on duty, medications regulated.

We can give you stories in comparison to other agencies who do provide day care where these kinds of services are not provided.

We could have given you this at \$17 a day on an intermittent basis. Not everyone would have attended. We would have been able to serve well over 275 clients per year.

Our projections were that 50 percent of the clients would come full time. The remaining portion would come part time, either 1, 2, or 3 days a week or for half days of the week, thereby maintaining probably the most important aspect of their life that lets them live longer and healthier with family contact.

Senator PERCY. Finally, Mr. May, I'd like to ask you this question. In the film, we saw a mouse. I don't know how prevalent mice in

kitchens are, but among elderly people, particularly, mice are somewhat disconcerting.

Do you think a reasonable effort should be made by nursing homes to keep themselves free from such animal life that might be disconcerting and might detract from the feeling that there is a sanitary condition and standard being maintained in the kitchen?

Mr. MAY. Absolutely, I agree with that completely, Senator.

Senator PERCY. Do you disagree with sworn witnesses that I have talked to that have testified they were instructed by the owners of the—I'd say in this case unscrupulous owners—nursing homes that they were instructed to feed people in four shifts and as there was food left on one plate from one shift, move it over to the next plate? Can you disprove or have evidence of the testimony given to this committee on those points as false?

Mr. MAY. If there was sworn testimony, how can I disprove it, but was that information current as of this year?

Senator PERCY. That I don't know. That was done 7 years ago, but there was allusion to testimony in the previous panel that food is moved from one plate to another in the second serving.

Who was the witness that testified to that? Are they still here?

Yes, Barbara Klein. Would you care to reiterate again what you actually saw?

Ms. KLEIN. In that particular circumstance, it was a plate that had been returned untouched by another resident. It was cold, and it had been originally intended for another person, but it was taken and given to a resident who had not been served a tray.

Senator PERCY. But it was an untouched plate. Then I misunderstood that.

Ms. KLEIN. That's right.

Senator PERCY. I thought that you had reference to the situation which we had uncovered, which is not an uncommon practice, in a few of these homes, 7 years ago, and I hope that that practice has stopped.

Do you disprove or have evidence to prove that hiring of untrained and unqualified personnel, which was prevalent in hearings 7 years ago, and once again was testified to before this committee today, has stopped virtually and that only qualified personnel are being hired by nursing homes in Illinois?

Mr. MAY. Senator Percy, I return to my testimony, and we did find allegations in the BGA report, but there are many positive things that are going on right now, both within the industry and the State administration to correct these difficulties.

We are supporting the nurses' aide training bill. There was a recommendation of a blue ribbon panel to the Governor that nursing home administrators no longer be licensed. We oppose that.

We are behind many things that would ameliorate the conditions of care, the nature of employment, the qualifications. All these things we are for, and I don't think that they've really been brought out sufficiently by this panel today.

Senator PERCY. Well, I appreciate the suggestion on that.

Do you support alternatives to long-term care or nursing home care if they can be made available, and do you agree that such services are not now really available?

Mr. MAY. Absolutely. We think that they should be expanded. We also feel the proprietary facilities should have an opportunity to have access in title XX funding for alternative care.

We think in some rural areas, they are the only health care facility within many miles, and they could provide these services very efficiently and effectively.

Senator PERCY. Now, I would like to read into the record the note that I received:

It would appear to this member of the audience that there exists an obvious bias against the service providers as distinguished from the BGA, who are obviously cronies of the special committee. For purposes of the record, I have no affiliation to the service providers, and therefore, I would urge a more impartial role on the part of the committee and its chairman. Charles W. Hannon, JD, practice management consultant, medical and dental, Schaumburg, Ill.

I can assure Mr. Hannon the Chair has no real bias. I have leaned over backward. You've read many books on the elderly, nursing-home care, and I have read them, and they are sensationalized, and they sell a lot more than I've sold of mine because I insisted in putting balance into it and telling the good side as well as the bad.

Obviously, the purpose of this hearing is almost like the public media. If you fill the newspaper with all the successful and happy marriages, you wouldn't sell many. If you told and filled the newspapers about all the people who got home safely at night and all the happy lives that were led and no acts of crime, you wouldn't sell very much.

I must admit that the purpose of a senatorial hearing is to pick out things that aren't going right and try to rectify those, and to that extent, we are looking for wrongdoing, but I always try to balance that out by paying particular tributes to those who are doing a good job as is evidenced by two of our witnesses here today and reached by a third, Suzanne Weiss, who's trying to provide a service that we feel is important and necessary.

I'll admit in the very nature of the hearing, it sometimes tends to be more negative than positive, and to that extent, I'm generally a pretty positive person. I'm fulfilling a role that this committee is charged with of trying to do everything we can to try to correct conditions and improve conditions. You pretty much do that by mainly pointing out what's going wrong.

But I have tried and I've instructed the staff to make certain we balance it out.

If there are no further questions, we'll move right on to our third panel. I thank you very much for your presence here, and Miss Weiss, we look forward to a new relationship with you.

We have three remaining witnesses who will testify. First, will be Arthur Quern, Patricia Nolan, and Dr. Desai Prakash. They will give a joint testimony. We also have Edward Stec and Robert Ahrens.

Once again, the Chair will invite our witnesses to summarize their statements, if they possibly can. The full statements will be incorporated in the record, but I do want to leave time for questions.

We will start with Edward Stec, Director, Office of Health Standards and Quality, Region V, Department of Health, Education, and Welfare.

**STATEMENT OF EDWARD STEC, CHICAGO, ILL., DIRECTOR, REGION V, OFFICE OF HEALTH STANDARDS AND QUALITY, HEALTH CARE FINANCING ADMINISTRATION, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE**

Mr. STEC. Thank you. I do not have a prepared statement but could make one available. I did mention to your staff that I wasn't aware until yesterday that I would be testifying today.

What I would like to do, however, is talk a little bit about my job, about the organization.

A VOICE. Can't hear anything. I don't think the mike is live.

Mr. STEC. Let me just recap very briefly. What I would like to do is just state my name, the organization I'm with, how we do fit into the picture, and why it is pertinent for me to be here and comment on some of the things that have been mentioned.

My name is Edward C. Stec. I'm with the Health Care Financing Organization, specifically the Director of Health Standards and Quality Bureau.

Now, the Health Care Financing Administration is relatively new. It was formed after the March 1977 reorganization within HEW. What Health Care Financing Administration did will perhaps help some of the problems that have been talked about constantly. It did put within one administration, within HEW, the major programs that are involved with funding, with standards and quality, PSRO, et cetera.

In other words, it took medicaid, which has, in partnership with the States, the sharing of funding, with States put into the same organization as medicare, which is the Federal program that makes direct Federal payments to providers and suppliers of service.

It also put together Health Standards and Quality Bureau, which is probably the most complex of the reorganization, because prior to reorganization, long-term care responsibility within HEW were just all over the ball park. There was some responsibility for regulation writing within medicaid because they deal with the same State agency. There was some in the medicare bureau and medicare also wrote all of the regulations for the other type of providers that are subject to State agency inspections.

It took the Office of Long-Term Care, which was the organization that dealt with nursing homes, and made it part of this organization, and also took out parts of Public Health Service that acted as consultants, put it all into Health Standards and Quality.

We did merge about 1 year ago, and I might say that some of the comments that have been made, and some of the activities have been discussed and offered here, require that I define how we fit into the long-term care picture, areas in which we have direct responsibility and areas in which we have oversight responsibility.

I think the first thing to mention is that the term "nursing home" is a very general term, and we have talked about various agencies administering nursing home programs, comparing it with home health agencies or hospitals.

Through my experience, I don't think you have different types of definitions for a hospital or for a home health agency. A home health

agency was really created with the medicare law, where it did define what types of service would be covered by the medicare program. Regulations were written to define what kind of agency can provide this service.

However, with the nursing home, the first attempt at Federal regulation was to implement the medicare law and make payments for extended care coverage in 1967, and as a result, we did, through the conditions of participation, I believe, define what is an extended care facility.

This was about the only Federal direction, although payments were being made under the medicaid program for nursing home care. In addition, payments were made to beneficiaries which were turned over to nursing homes, but there were no Federal standards until 1974, when the ICF, the intermediate care facility, was designed.

A very important difference here is that with the skilled nursing facility that's participating in the medicare program, the provider agreement with that particular facility is with the Federal Government, with our office.

I do sign off on SNF, title XVIII, provider agreements. I do notify of terminations, approve withdrawals, or indicate that a facility was not qualified and issue denial.

With the intermediate care facility, we have more of a monitoring role. Now, the payment is matched by the Federal Government to the State, which does make payments for these types of services.

Basically, we're probably more involved with form and substance in our monitoring program. The ICF provider agreement is between the particular State agency and the home. Surveys are conducted by the State.

We do get involved in saying whether the proper forms are used, et cetera. I think we do concentrate too much on that.

Again, as far as terminating Federal participation, it's very questionable under what conditions we can terminate Federal participation to an ICF.

One thing I do want to make clear, we do not put a nursing home out of business. What we can do by an adverse action, such as a withdrawal, a denial or a termination, is indicate that Federal funds cannot go into the facility. This is the extent of what, by law, we could do.

We do not get involved in local licensure, et cetera, except that the conditions do require that if there are State and local licensure requirements, the facility does have to meet them to qualify.

I might also mention, finally, that we did conduct hearings here in Chicago on July 11 through 13, in this particular building. Several of the people who have testified here also testified at those particular hearings.

What we have done over the last few months, especially when we've gotten our reorganized group together, is just to look at the regulations.

I think we pretty much decided that we do concentrate more on process than on measuring quality of care.

The hearings were well attended. I believe nationally, they were held in five different locations. Something like 400 formal reports were submitted. We had very heavy attendance here in Chicago on all 3 days.

I might mention that by and large, we were told by the public that the standards that we developed for States to use in ICF, and the standards that we developed for skilled nursing facilities, should be aimed at quality of care.

The problem again is that we didn't get too much in the way of direction as to how we do define quality of care.

I am confident, however, that if we do not have legislation, the regulations that will be rewritten will make another attempt to concentrate more on measuring quality of care and the process itself.

I want to make one additional comment. We do recognize the need to experiment, and the State of Illinois does have a system which they did submit, they submitted to us at the hearings for consideration in rewriting the regulations. That's the QES system that was mentioned earlier.

The State of Wisconsin has had another experimental system approved several months ago which is called Triage, which is a different type of attempt at concentrating more on facilities which have problems, less on facilities which are operating quite well. It's quite an interesting program. We're trying to use our experimental authority to overcome regulatory requirements. We have approved it and are in the process of implementing this system.

Those are about all the comments I have.

Senator PERCY. Thank you very much, Mr. Stec. I appreciate that.

Now, we'll hear from the State of Illinois, and we have with us Arthur Quern, director of the Illinois Department of Public Aid; Dr. Patricia Nolan, associate director of the Office of Health Facilities and Quality of Care, Illinois Department of Public Health; and Dr. Prakash, regional administrator, region 2, Illinois Department of Mental Health, Chicago.

Mr. Quern, are you going to speak on behalf of your group?

**STATEMENT OF ARTHUR QUERN, DIRECTOR, ILLINOIS DEPARTMENT OF PUBLIC AID, SPRINGFIELD, ILL.**

Mr. QUERN. I am, Senator.

Dr. Walsh is here in place of Dr. Nolan from the department of health, but I will make a statement on behalf of the State and the other State representatives, and I will try to answer any questions you may have.

A VOICE. Can't hear back here.

Mr. QUERN. Senator, we have a mike that's not working. I'll try again.

My name is Arthur Quern. I am the director of the Illinois Department of Public Aid.

Senator, I will make a brief statement on behalf of the State representatives.

I am joined by Dr. Walsh of the State department of public health, Dr. Desai Prakash of the State department of mental health, and we will be trying to make a brief statement and answer any questions you might have.

The State's role can be stated rather succinctly. It is our responsibility on behalf of those who are eligible under the State laws to purchase or provide directly appropriate levels of medical care and

nursing care at the lowest possible cost, the lowest reasonable cost available, and provide it in a facility or in a program which is approved and licensed and which is geared to provide that individual with the highest level of independent living possible for that person.

Now, the implementation or execution of this mission is what we are talking about today in many of the items that have been discussed before this committee.

I think what I would like to do is to attempt to address those major areas which have been raised and then leave to you any questions or other details which either we do not address or which you would like to add to the picture.

Since we have been in office, in the Thompson administration in 1977, we have been looking at and concerned with the reimbursement system for nursing home care, along with a number of other questions of reimbursement for medical care under the medical assistance program.

At the current moment, in the most recent fiscal year, we purchased on behalf of 46,000 citizens, \$250 million worth of care. In the coming year, we expect that same amount of assistance for that same number of individuals. The cost to the State taxpayers, approximately \$285 million.

What we want to do is to assure that that money is well spent and spent in a way that provides individuals with quality care, but we also want to do it in a way that does recognize limited resources and the pressures of cost containment. In all areas of the health industry, cost containment is a must, because if the State and public sector is to continue to respond to this kind of need, it must do so in a way that is cognizant of the limited resources available.

What we have done is effective January 1 of this year, a new cost-related reimbursement system was instituted. With that system, we did a number of things. We attempted to accomplish a number of things.

First of all, on the average, rates went up about 14 percent. We recognize that for a number of years, the rates that the States were paying had been below actual costs, so in January of this year, rates did go up.

In the coming year, under the same reimbursement system, rates are expected to go up again. That increase will be based on actual cost reports that will be submitted by the nursing homes, and then under the formula which we have established and has been approved by HEW, we will take those costs and compare them. We will take a look at one facility, its costs, and compare it with other facilities and attempt to strike a reasonable balance to find an appropriate level of reimbursement which actually reflects costs out there and at the same time does provide a reward for efficiency.

This is a system that we have instituted. We just started it this year. We are carefully watching it to see if it accomplishes those things or helps us accomplish those things.

We do believe it has improved our ability to respond to costs out there. The 14-percent increase is already showing up in the rates that are being provided, and we expect about an 8-percent increase based on inflation this year to be effective in January.

But I think it's important to point out there are only so many things that a reimbursement system can do. No matter what system you structure, the unscrupulous will always find a way of squeezing the dollars out of the intended care and putting it into their pockets.

We believe that by careful auditing, careful reviews of these facilities and careful comparisons amongst facilities, we can minimize this kind of misuse of public funds.

There will never be a system which will totally eradicate it. I do believe we are on the route of substantially improving our ability to reduce it.

Another area that was addressed time and time again this morning is the question of patient assessment. We've talked about the point count system and its shortcomings. The ability of anyone—the State, the bureaucracy, the medical industry, the medical professions—to measure the need for quality care, the need for care, is an ability which is not perfected. It is one which is not agreed upon. It is one which has posed great difficulty for everyone.

We recognize the shortcomings in the point count system. We do believe it reflects some actual need and does give us a tool for measuring the needs that patients have for the kind of care they would require in institutions.

We also believe it's either got to be improved, modified, or else replaced, and we are working with the industry now to seek better patient assessment tools.

But here again, I've got to make the points that any patient assessment tool is likely to pay more for care for those who are in more serious need. One of the criticisms of the point count system is that it rewards a facility if it has a resident who is in greater need for care.

Almost any medical system of reimbursement for patient care is going to pay for those who need greater care. What you must seek to do is to try to take out any disincentives to good care. You must seek to try and review the kind of care that's being provided in response to the patient assessment tool, whatever it is, and regularly compare that among facilities and have it reviewed by professionals.

This is what we're talking about with the medical industry now, with the nursing home industry, what kinds of tools are available.

In conjunction with this issue, the Department of Public Health, has proposed that the QES system which was developed in the past be tested in the next year on a pilot basis to see what it does tell us.

We are also going to take a careful look at what is done in other States to see if anyone else has learned enough about this kind of issue that we can benefit by their experience.

Another issue that was repeatedly brought up this morning is that reference to the number of State agencies involved in overseeing the kind of care that's provided in nursing homes in this State. There is no question that there are a variety of agencies, and we are very cognizant of it.

At the present moment, given the organizational structure, we seek to minimize overlap, and we are seeking to assure communications. We've done this in a number of ways.

Governor Thompson created something called the purchase care rate review board in which all of the major agencies which are involved

in purchasing care—medical care, primarily—on behalf of citizens in this State, meet at least once a month, review their reimbursement system, and review the principles upon which they agree to pay and reimburse people for care provided.

We have also begun reviewing our mutual or our respective regulations to assure that one agency isn't issuing a regulation which is going to have a significant impact on people in nursing homes and in other agencies such as public aid, which is paying a great deal of that cost, is not aware of that regulation, so we're going to take a look at all regulations that the State issues before they are issued to assure that everyone knows the fiscal impact and the programmatic impact of the programs involved.

We have begun doing this. We think it bodes well for cooperation among the agencies, and as long as a structure is as it currently is, we are working to assure communications between these agencies. In addition, Dr. Peterson, who is the director of the Department of Public Health, is, at the request of the general assembly, currently looking at all of the roles of the different agencies involved in reviewing and investigating, paying and licensing, certifying, et cetera, these facilities to see what consolidation makes sense, what it would cost, what would you lose in consolidation.

Here again, I would caution you in one sense: The consolidation can lead to a loss of checks and balances. One monolithic agency, which is the only public entity dealing with a nursing home, could be subject to self-protective kinds of attitudes, and if it didn't have the kinds of checks and balances it currently has, where different agencies and different representatives of different public organizations are in that facility, you might not have the same amount of checks and balances.

That's not to say we have enough now and it's not to say we're ruling out consolidation. It is just to say that we want to keep that in mind. We don't want to create a monolith which is going to replace the current faults with a new set of faults.

Senator PERCY. Has the commission set up by the Governor, headed by Mr. Freeman, former chairman of the board of the First National Bank, gotten into this area and looked to see what can be done to consolidate, streamline, and make the decisionmaking more effective?

Mr. QUERN. There were over 670 recommendations in that report, and I know of at least 10 or 15 recommendations which deal with one part or the other part of the nursing home industry and review.

Senator PERCY. Do you support those recommendations?

Mr. QUERN. Some yes and some no. We're reviewing them right now. We're not sure all of them would save as much as they say. We are not sure that they can be implemented in the fashion they suggest.

Senator PERCY. Would it be possible, then, in a period of a week to 10 days to give us an analysis of those that you fully support, those that you do not support and those that you're still open for question?

Mr. QUERN. Senator, we have about 70 under review right now. I'm not sure I can meet your time limits, but I certainly would be willing, as we finish our process this fall as part—

Senator PERCY. I think it was quite an inspiration to set up this absolutely top level commission, one of the finest things done by any

State. I think that other States would benefit very much by the analysis they've made in this field. Also, I'm certain the Governor didn't appoint that commission feeling that the recommendations would be accepted 100 percent by the director of the department. But, on the other hand, if you can give us an evaluation, I think it would be very much appreciated, and I'll order that the record be held open so that we can get that report from you.

Does that about conclude your comments?

Mr. QUERN. One final area, Senator, that was brought up a number of times this morning, and that is alternatives to home nursing care.

The Governor, since he's taken office, has been very strong on this as a major priority, and we have been working with the general assembly and with many others to find various means of assuring that there are alternatives to nursing home care and today, the Governor will sign a bill—House bill 2691—which will provide up to \$6 million in the current fiscal year for care, home care, to help people stay out of institutions.

We think, working under that bill, working with that legislation, we can have a very good test and a very good look at what will happen if home care is available and home care alternatives are provided.

We do, I must share with you, have some concerns that there will be instances of expanding the needs as opposed to responding in alternative ways, but the Governor has directed us to go ahead with this bill. He's signing it today. It will provide up to \$6 million, and we think in the long run, it will give a very good test to see if this idea works and alternatives to home nursing care provided in the home can help individuals and can help the State.

Senator PERCY. Thank you very much.

Director Ahrens, you will conclude our comments, but I would like to say that on the day of the mayor's marathon, we were at dinner together with all the marathon runners across the country. He had that day gone out to visit the new senior citizens center on Milwaukee Avenue. It was really an inspiration. No city cooperated more with Senator Kennedy and I than the city of Chicago in setting up nutrition centers, really doing an outstanding job. You provided a model that I talked a great deal to the rest of the country about, to convince them this is one of the finest things they could ever go into.

I think these centers have been a 10-year battle of mine to see that we don't just build centers for youth on campuses. Every campus in the country has got a student union where students can get together, but you have to go to St. Petersburg, Fla., to find a good center for senior citizens.

They've got all the time. They've got the desire to get together. They want to be with each other, and there are the physical facilities, and to think of us setting them up in the city of Chicago, whether you use Federal revenue sharing or not, I don't care, it's one of the best uses you can put that money to.

I think you have really distinguished yourself in your leadership in this field. I know, also, the city of Chicago, under your leadership in this area, has been constructively looking for alternatives to nursing home care, and I think you pioneered again in that regard. I was so delighted to have the industry itself testify that they constructively look forward to this, feeling that institutionalization is not always the answer for a person's needs.

Your reputation across the country is well known in this field, and I always feel privileged to work with you and the State government to provide a real model for the Nation here in Illinois.

We need an awful lot of things. It is not enough to lead in agricultural products and in the export of agricultural products. We have to lead in the caring for human beings in a dignified, fine way.

I think, probably, our lifetimes would be well worthwhile if we do that. So it's with that sense we have invited you to appear here, and we're very grateful to you and Arthur for being here, as well as Dr. Prakash and Dr. Walsh, and of course, Mr. Stec. You obviously have a great responsibility in this area and I've worked with Secretary Califano, and I know his dedication in this field, also.

**STATEMENT OF ROBERT J. AHRENS, DIRECTOR, MAYOR'S OFFICE  
FOR SENIOR CITIZENS AND HANDICAPPED, CHICAGO, ILL.**

Mr. AHRENS. Thank you very much, Senator Percy.

As you said, we've been through some battles together when we pioneered with nutrition programs back in 1968 to get them established, and finally—

A VOICE. Can't hear back here.

Mr. AHRENS. I was just saying we worked together back in 1968 and 1969 to pioneer what is today a national nutrition program for older people, and I have appreciated the opportunity, also, to work with you.

I really ought to say I'm here, of course, as the director of the mayor's office for senior citizens and handicapped, but—

Senator PERCY. Bob, could I interrupt you for just a moment, because I know other people have pressing appointments?

We will be trying to wind this up in 5 or 7 minutes. My questions are very short, because your statements have been quite complete.

I will have a summary statement of a minute or two, so the people can count on, I think, leaving the room just shortly, 5 or 10 minutes before 1, to make their 1 o'clock appointments.

Mr. AHRENS. I wanted to make a statement, also, as the president of the urban elderly coalition, which is an association of the offices on aging of the Nation's cities, that we regretted very much this summer losing a member of our staff, but since we lost him to the respected staff of the Senate Committee on Aging, we don't feel so bad, and I'm sure that Jeff Lewis will do an outstanding job for your committee, as he did for the coalition at our office in Washington.

Senator PERCY. We're very proud of him, too.

Mr. AHRENS. I have a brief statement, but there are a couple of points I do think important that I add to it, because they are critical of the State of Illinois and I may as well do it while we're all here.

A House subcommittee has concluded that there are from 2 to 3 million noninstitutionalized aged persons who are bedfast, homebound, or have difficulty in getting outdoors without help. Nationally, the population aged 75 and over is growing at almost twice the rate of the older population as a whole.

In Chicago, persons age 75 and over increased by 31 percent between the 1960 and 1970 census; those 85 and over increased by 65 percent. While no one age group among the elderly is necessarily frail, the Federal Council on Aging has noted that dependency-creating

elements are more likely to occur among the more aged groups of the elderly.

A recent survey in Illinois by Booz, Allen, and Hamilton confirms again what most practitioners in aging have always known: The elderly in our Nation want to remain in independent living in their own communities and out of institutions for as long as it's wise and possible to do so. It's always been a chief goal of our office in Chicago to try and develop the home and community based systems that will support this.

Our office does provide some basic services, such as home help, homemaking and home-delivered meals to some of Chicago's elderly. However, the funding for these programs, made available chiefly under titles 3 and 7 of the Older Americans Act, with some under title 20 of the Social Security Act, is extremely limited. Our research division has estimated that 10,000 elderly and younger handicapped persons in Chicago need home-delivered meals. With present funding, we can serve only 1,100 daily.

Many agencies are ready and willing to develop supportive services as alternatives to prevent unnecessary institutionalization, but funds are lacking. We need to alter those policies which have directed most financial resources to support of long-term care proprietary institutions. We must change the medicare and medicaid legislation to include a full range of in-home services.

The restrictions placed on home health visits under medicare ought to be eliminated and the range of services should be expanded. We agree with recommendation 6 of the Subcommittee on Health and Long-Term Care of the House which recommends that a full range of homemaker and correlative services be added to medicare's current coverage of home health services.

The kinds of services such as friendly visiting, housekeeping, home repairs, transportation, home-delivered meals, are absolutely necessary supplements to a continuum of in-home health services.

We support the concept of Senate bill 2009, introduced by Senator Domenici, a member of your committee, which proposes to eliminate several prerequisites to receiving home services under medicare.

In most States, home health care agencies are not required to be licensed, and standards are lacking for training of home care personnel. The frail or vulnerable elderly must be served by well-trained, well-supervised, competent workers who deliver quality service in accordance with recognized criteria.

Opportunities for abuse of these clients must be eliminated. There is no point in trying to eliminate abuse in institutions and then face it again in an alternative system, so we do need national standards to insure the provision of quality in-home services, and these standards ought to be developed through consultation with service providers and the elderly as well as with planners and advocates so that we get standards that are workable and can be implemented quickly.

These standards for in-home services ought to include criteria for service delivery as well as for selection and training of service personnel. Provision must be included for certification of providers who meet the standards and severe penalties for those who abuse clients.

If quality care for the homebound and bedfast is to be insured, then HEW must develop national standards for a full range of quality

in-home services with effective controls to avoid the abuses that have arisen in the long-term care institutions.

Furthermore, the provision of in-home services to the elderly, funded through a variety of sources, including title 20 of the Social Security Act, should be closely coordinated through the designated area agencies on aging, which have the overall responsibility for planning services, so as to avoid duplication and maximize quality and efficiency.

This is an extremely important point, for the failure of States to work through the area agencies on aging in Social Security Act title XX programs for the elderly, can make the coordination responsibilities of the area agency on aging under title III of the Older Americans Act an impossibly difficult task.

I think the Congress may well want to review the effectiveness of the coordination of titles III and XX programs at the State and local levels.

And here, Senator, I think it's important to add that I do think it is disgraceful that the State of Illinois has failed to access any more than 53 percent of title XX social service funds for the last year. Excuses for this just do not hold water, and I think the U.S. Commission on Civil Rights Age Discrimination Study findings, which also pinpointed that even those title XX funds which are spent do not go to the elderly, in terms of their proportion of the population, is equally true here in Illinois. It all indicates that there is a lack of priority in Springfield for social services.

If we paid some attention up front to these kinds of things, I think we would have to pay less attention to the kinds of things which have resulted in this hearing.

The whole title XX plan for Illinois includes nothing for home delivered meals.

While we have waiting lists under title VII of the Older Americans Act for meals programs, the State of Illinois does not put 1 cent, Senator, into the nutrition program for the elderly. The city of Chicago and HEW have come up with millions of dollars for these nutrition and multipurpose centers that both you and I think are so necessary and valuable. The State must do more than be a silent partner, I think, in the delivery and funding of social services for our older people. The burden should not be left alone, I think, to the Federal and local governments.

Finally, because of the nature and severity of the impairments of many older people, while only 4 or 5 percent are in institutions, that percentage can be expected to continue to require long-term care in an institutional setting.

The responsible public agencies, whoever they are, must establish high standards for patient care, plus vigorously enforce these standards and I mean Federal, State, and locally.

The public will no longer tolerate profiteering of the nursing home owners who fail to provide quality care for their patients.

Thank you for the opportunity to present my statement. I know that the views I've presented for our office on the need for home and community-based services are equally the views of the urban elderly coalition and also the National Council on the Aging, whose public policy committee I chair.

Senator PERCY. Thank you very much.

I'd first like to ask a question of all of you. Do any of you feel that BGA and the news media provided a public service by focusing attention on this particular issue?

Mr. AHRENS. Senator, I wish they would do even more. Let me give you an illustration.

Going back to 1968 and 1969, I wrote a letter to the editors of all of the Chicago newspapers, enclosing copies of the study we had done on the likely effect of this wholesale putting people out of State mental institutions, asking them to look into it and perhaps devote editorial time to it. Nothing resulted.

Now today, we're having exposés on that problem.

Again, I wrote to every television and radio station manager here in Chicago, and to the press, prior to the title XX hearings a couple of years ago, to determine the State social services plan.

I said I had read nothing in the newspapers that would even explain title XX to the public, let alone urge them to come out and testify.

Again, I think the media, if it would really take up its responsibility, would do more. It would do these basic things up front, that would diminish the need for exposés that have to come later, and would perhaps eliminate some of this intolerable abuse where it exists of old people.

Senator PERCY. Considering they could do more in our particular fields of interest, even more, do you feel, though, that what they have done, focus attention, has been in the public interest?

Mr. AHRENS. Indeed I do.

Senator PERCY. I think there seems to be a concensus.

Mr. QUERN. Senator, I'd just like to say two things: One, that the report by the BGA and the channel 7 report dealt with about eight nursing homes. There are specifics in there that we'd like to address independently in a written statement to you, but I think you point to a very key word here—and indeed, the investigator for the BGA used the same word earlier—"attention."

He said it was not so much abuses as it was inattention.

You've also heard today about all of the State representatives tripping over each other coming in and out of facilities. Somewhere in here, we need to focus on the proper roles of all of the various entities involved in nursing home care, but one thing that comes back to us, we run a large agency. There are a number of agencies involved. The statistics that we have—I can't assure you that they are the most valid or best sample kind of statistics, but our best information shows that up to 60 percent of nursing home residents have one or fewer visitors a year.

One of the things that happens today with this hearing, with the BGA report, is a question of public and family and community concern. We are large agencies. It's healthy for us to be interested about what we're doing and where we're headed.

Nursing homes and institutions—it's healthy for them to get questions in this form, but until families are concerned and communities are concerned, there will never be enough inspectors. There will never be enough monitors 24 hours a day to watch every patient and watch every nursing home, so the point that has come through all of

this is a question of attention, and I think that's been the most significant point of all.

Senator PERCY. I might say in most of the audiences that I address I will get around to the fact, as I did yesterday, that probably in your neighborhood, you have a nursing home. You walk by it a number of times. You just never turn in and see what is going on.

I wrote a letter to every single high school in Illinois and got high school students to visit nursing homes. Some of them testified that they just literally were thrilled that they were wanted.

Drug abuse is worse among young people and old people. Why? People in the middle stream of life—being active, busy, making money, providing for families—feel important. But the younger people sort of are left out of the bigness of society, and they cop out, in a sense, and the older people feel left by the wayside.

Put the two groups together. Some of the young people from Mundelein College were 10 feet tall as they went into those nursing homes at Edgewater in Rogers Park. They went in and combed the ladies' hair, helped them answer letters, helped them make phone calls, just sat and read the newspaper with them, talked over current events, started calling each other "grandma" and "grandpa" and "grandchildren," and so forth. It was just a wonderful thing.

So there's an awful lot Government can't do, more they can't do than they can do, really.

Some of those people have only one visitor a week. They grab onto you, they hold onto you. They're so anxious to touch a human being and just feel that someone cares about them.

That's something Government can't provide.

The purpose of these hearings many times is just to prick the conscious of people as much as anything else, and I appreciate very, very much your mentioning it.

I'm wondering, Mr. Quern, whether you could address yourself to the question regarding Accom-O-Day and the donor matching which legally disqualifies the witness that we had before, the director of Accom-O-Day Care Center in Chicago.

Mr. QUERN. Certainly. I personally visited Accom-O-Day, and we looked into working with HEW to develop a pilot to see if we could pursue that. We were not—we did not get approval to use title XIX funds in that fashion, so then we went the title XX route, and I want to mention we, too, are concerned about title XX and this State's ability to get its entitlement.

I think we're there. I think for the first time, Illinois will reach its ceiling in the fiscal year.

One of the things she was referring to was part of the Governor's initiative under title XX to involve the private voluntary sector in the use of title XX funds, and we had hopes, in the absence of HEW approval, to use title XIX for that facility, that we might try to use the volunteer sector to come up with the donation.

We would share the leverage which title XX provides for reimbursement and let that money go directly to this kind of program.

I did not know Ms. Weiss' problems with that till I heard her statement here today. I take it she found some of the discussions with the private volunteer sector inadequate and therefore, has decided to not proceed with that.

The only thing I can say is, as a next step, I would hope that we would sit down again when the Governor signs his bill today, he does provide an additional resource. It may provide a means for taking a program like Accom-O-Day and giving it a run for its money to see if it works.

I cannot leave that statement, though, without addressing a question that you raised a number of times, that is, are we sure that it's really going to keep people out of nursing homes? We are not sure.

I think it may just respond to a need out there in the community which is not being met, lonely old folks in their homes who aren't getting any kind of services. Whether or not it provides an offset of nursing home costs is something we'll study.

That's an interesting cost-benefit analysis. We think it's worth exploring in terms of home health care services, so what I would like to do with Accom-O-Day, once the bill is signed, once we have begun developing the regulations, to sit down with them again to see if there's a means of using them.

Senator PERCY. Very good.

Incidentally, I spend a great deal of time on case work with Senator Stevenson, who was invited to be here to participate with me. Regrettably, his schedule did not permit him to do so, but our offices work together on a lot of case work involving patients in nursing homes, nursing homes themselves and so forth, because they know of my interest.

I had one call come in last night, late, asking for an appointment with the Governor to work out a problem. I said, "Why the Governor? We've got the expert coming today."

If Mr. Grisham could turn that case over to you, I'd appreciate your giving us some judgment on it as to what could be done.

My last question really pertains to whether you feel lines of delineation between Federal, State, and local government are clear enough, whether their responsibilities in this area are sharp and clear.

Do you think there still needs to be work done in that area to eliminate the overlapping, duplication, to clean up the lines of authority and responsibility so each level of government knows what its duty and responsibility is and authority?

Mr. STEC. Personally, I think it is clear.

My problem, what I tried to address myself to very briefly, is the definition of a nursing home is a very wide definition. The Federal Government just has control over a very small portion of direct control and a monitoring role in another portion. I would think, by and large—

Senator PERCY. Your area mainly is intensive care.

Mr. STEC. Right. We had about 800 of those in the region where there were about—

Senator PERCY. Intermediate?

Mr. STEC. We don't even have a count on a role in residential facilities.

I think from the standpoint of what we've done, I think we have had fairly good relations with the State. I think we've given some pretty good training and interpretation of regulations.

Now, keep in mind, I think our regulations were too process-oriented, but I know in Chicago, we started basic training courses which I think the States do like quite a bit. We are funding some of

the surveying activity, which I think does help, and if you look at many States, they have developed some fairly strong licensure laws which do help in enforcement.

Again, I think the question is how far should regulations control nursing homes go, and that's the question I would, you know, prefer to comment on, at least officially.

Senator PERCY. Thank you. Just a very brief comment. We will adjourn in 1 minute.

Mr. QUERN. It is not as neat as anybody would have. I think we know our functions. Now they've got to be improved.

We are involved in paying bills. Other State agencies are involved in licensing. Others are involved in approving patients' programs.

We terminate medicaid providers such as we terminated eight nursing programs in the last year. Public health has been involved in licensing, reviews, and they have suspended one license in the last year, and there have been over 50 in hearings at various times.

These roles are defined now, defined in the most sensible way. Are there better ways to consolidate?

I would have one other thing. I can't pass it up, and that is one major factor is the cost, and Illinois, as with a number of other big, industrial States, only gets 50 percent reimbursement by the Federal Government, whereas many other States are getting as high as 80 percent.

Our \$285 million could go a lot further if we were reimbursed at the rate of some other States.

Senator PERCY. Very good.

I think at this stage, I'd like to just summarize a few of the conclusions that I have come to. This has been a good hearing and you always want to keep going. You finally have to have a terminal point.

As I said in my opening statement, the committee really is here today to update our previous studies on nursing home conditions.

We've heard testimony about some deplorable conditions, and we've heard testimony about some good conditions, so we know that there are, in some areas, high quality care being provided, and that it can be and should be provided.

We're not talking just about a million people in nursing homes. We're talking about 5 or 10 million people who have families in them, who are concerned about them. We're talking about everyone in America that may end up in one, so we've got a problem to see that today we do have a better coordinated governmental program, so that we can see who has the responsibilities, and that the buck stops someplace. If it's the Federal Government role, I want to see that we assume that degree of responsibility.

We're going to try to streamline the bureaucracy in every way that we possibly can, to better monitor the quality of care in nursing homes and define what we mean by quality care.

I think we have seen improvements, but we also know that we have problems, and we have still a long way to go.

The area that I think we all can work on together more is expanding extended care services in the home. Personally, I have seen so many people who could have saved the State \$400 a month or \$500 a month if they just had some service for a while that would have bridged them over. They'd much prefer to stay in their neighborhood, their communities, wherever they happen to be living, and I've

talked to those people in their homes. We are really trying now at the Federal Government level to reach out and expand the meals-on-wheels programs, home-delivered meals, extended home care, and this is the area that Senator Domenici and I are beginning to work in very, very closely.

We mention a little of the arithmetic. Let's talk now about taxpayers' dollars. We're spending someone else's money, and I did it for years, spending stockholders' money, and now I think I have to look at this as carefully, more carefully than if I were spending my own money.

Just last year, we spent, at the Federal level, \$6.39 billion by medic-aid on nursing home expenditures.

As Everett Dirksen said, "A billion here and a billion there, and pretty soon, you're talking about real money."

What I'm impressed by after 12 years in Washington is \$6.39 billion. At the same time, we're only spending, and I say "only," it's a lot of money, but relatively speaking, it's less than a tenth, we're spending \$458 million in medicare funds on home health care services.

It's obvious that if more funds were put to work there, you'd lessen the necessity for \$6.39 billion, and it's a better, more humane way to do it.

We just don't have the procedures and programs now. This is an increasingly elderly society. More and more people are living longer and getting older. We're increasing the working age. There's a lot of things that we can do there that we haven't even discussed, obviously, such as improving the social security system.

Between 1966 and 1975, nursing home costs to this country have risen 400 percent, and the higher proportion of older people in our society will cause those costs to skyrocket. Let's try to get a lid on those costs.

I am more fully aware than I've ever been of the commitment that I must make and my colleagues must make. I respect very much Senator Domenici, who has made this a major part of his activity in the Senate. Caring for the elderly is of paramount importance to us. They have to feel someone cares about them and is looking after their needs, and that they have someone that they can write to.

It's the role of this committee to explore problems which prohibit elderly persons living in nursing homes from obtaining quality care. It's our overall responsibility and duty to see that we somehow build the kind of quality into the lives of the elderly that makes their lives meaningful, that makes them decent. This Nation will be judged for the way we provide for the elderly, and we're not doing a good job of it today.

We've got a long way to go, but Chicago and Illinois have been leaders in so many ways. I think we're going to do a great deal to improve these programs as a result of this testimony today, and I'm deeply grateful to BGA, to the media, and to all of the outstanding witnesses that we've had today.

These hearings will be presented as official hearings of the Senate Special Committee on Aging. Copies will be made available to any of you who drop me a note and ask for them.

I'd like to thank our distinguished staff, both minority and majority, for their great help, and without further ado, this hearing is adjourned.

[Whereupon, at 1:15 p.m., the hearing was adjourned.]



## APPENDIX

### LETTERS AND STATEMENTS FROM INDIVIDUALS AND ORGANIZATIONS

#### ITEM 1. STATEMENT ON BEHALF OF THE WILLIAM RAINEY HARPER COLLEGE, PALATINE, ILL.

William Rainey Harper College, Palatine, Ill., in its attempt to be ever aware of the community's responsibility to its citizens, is acutely concerned with the lack of well-trained nurses' aides who are employed in long-term care facilities, geriatric centers, and home-health agencies.

It is with this concern foremost in mind that William Rainey Harper College, jointly working with CETA (Comprehensive Employment Training Act) is offering an 8-week geriatric/home health aide training program to enable eligible suburban Cook County residents to care for Illinois' elderly.

This program is designed to provide the highest quality of training in both the geriatric field and that of home health care. We feel that institutional care is not designed nor required for all senior citizens, so we do offer 12 clinical hours in the home health care setting as well as home health adaptive techniques taught within the classroom.

In addition to preparing students with basic nursing skills relating to personal hygiene, skin care, nutrition, elimination, ambulation, vital signs, activities of daily living, facilitating rehabilitative goals, observational skills, and reporting techniques, we include 16 hours of psychosocial aspects of caring for the elderly. We seemingly find that if students first are able to identify normal aging and the psychosocial aspects of aging, they then are better prepared to care for their patients. This preparation, we feel, is also responsible for satisfaction, longevity on the job, and a thorough understanding of that phase of development.

The need for nonprofessional nursing care personnel is critical in all areas of care to the elderly. For our particular purposes this need was identified in a January 4, 1977, publication, "Survey of Need for Nursing Aide Graduates in Home and Geriatric Health Care."

The purpose of this study was to determine whether or not there was enough employment demand for graduates of a nursing aide program for home and geriatric care to justify such a program at Harper.

The population surveyed consisted of all the home health care agencies and the nursing homes in the northern, northwestern, and western suburbs of Chicago. The results indicated an overwhelming evidence that there would be sufficient demand for graduates.

The most serious problem revealed by the survey was the estimated salary our graduates could expect to make. The survey of these home health care agencies and nursing homes indicates there is an employment demand for about 150 nursing aide graduates per year. However, because the hourly starting wages are low (\$2.54 for nursing homes and \$2.82 for home health agencies) there is a question as to how many students could be recruited each year.

Since the development of this concept began, our biggest concern is that of identifying students. The difficulty, it seems, relates again to the earning power of nonprofessional care-givers in the job market. Although most of our contacts in the health care field employed our students at a rate similar to those of "experienced employees, that rate remains significantly low. In addition, raises, advancement opportunities, and motivation seemed to prevent graduates from remaining at any one facility for long periods of time.

We approached the identification of students through local newspaper advertisements, contacts with health care facilities, as well as a myriad of other sources, which never quite filled the class enrollment. The best approach seemed to be in advertisements which were specifically interesting to homemakers who were

looking for personal enrichment. It appeared to us that these students were most successful with great potential for advancement. These specific students were mature, loving, giving, and sensitive to all the needs of the elderly.

Currently requirements for nonnursing care-givers is, as we see it, relatively nonexistent. Many facilities are so desperate for staff that training and experience are not criteria for employment. Some facilities offer a training program. Even though these training programs are well intended, they seem to be extremely fragmented and carried out in a catch-as-catch-can manner. Apparently, the difficulties arise from on-the-job training instructors having many other diversified duties, as well as students being responsible for care-giving without adequate skills or knowledge.

We fully realize that many attempts are underway to resolve the situation of unprepared nonnursing care-givers. Beth Walston, chief of Curriculum Development and Training Division of the Office of Health Facilities and Quality Care, Department of Public Health, is doing a commendable job in standardizing nurses' aide training. We were unable to offer input at the latest meeting as the dates for the Springfield meetings met with personal conflicts.

We are also aware of the efforts of Richard Whitney of Lieutenant Governor O'Neill's office, and have been in contact with him as he concentrates his efforts on behalf of legislation for nurses' aides.

The Illinois Health Care Association in Chicago also is concentrating the efforts to upgrade training of nurses' aides in the Chicago area. We also have offered assistance in this endeavor.

Our successes in the past year in training nonprofessional care-givers is not ours alone. In addition to the efforts of the local CETA offices and the expertise of the nursing faculty at the college, we have had considerable support from our advisory board. The advisory board consists of key figures in the local health care field. We have three representatives from home health facilities who have not only been a help in our development, but also instrumental in referring students and offering employment opportunities. In addition to nursing faculty representation from the college, we used the expertise of many representatives of long-term health care facilities and geriatric centers on our advisory committee. These contacts also have helped in offering employment opportunities.

The local social service agencies also are aware of our endeavors and from time to time send us referrals.

Our futuristic goal in terms of caring for elderly in the north and northwest suburban area is to concentrate on the training of the nonnursing care-givers in health care facilities. To effectively accomplish our goal, the emphasis seems to be on teaching others to care for others. The ability to understand the elderly, in our opinion, does offer some success in their caring, as well as being able to use basic skills to assure the elderly of the care and dignity they so richly deserve.

It might also be imperative that the monitoring agencies be fully aware of requirements and standardizations of programs and then be able to enforce these programs.

All in all, quality care begins with quality training. We, therefore, strongly recommend that:

- (1) Efforts to standardize nurses' aide training in Illinois continue through the establishment of firm training criteria and nurses' aide certification requirements. To be effective, these standards must be strictly enforced in all long-term care settings. Training programs must also be adequately funded and monitored to prevent "paper compliance" with established training standards.

- (2) Emphasis be placed on understanding the process of aging and the psychological needs of the elderly in all training programs. It is essential that instructors within these programs have geriatric and rehabilitation nursing backgrounds and possess a strong commitment to quality care of the aged as well as the ability to transmit these concepts and skills to the students.

- (3) The nurses' aide training program model described herein, which includes the joint efforts of the local long-term care agencies, the local community college and outside funding source such as CETA, could be developed and implemented in multiple community college districts within the State of Illinois. Widespread organized quality nurses' aide training should have a major impact upon the quality of care to our elderly if it is provided in conjunction with nurses' aide certification requirements.

- (4) Federal reimbursement programs to long-term care facilities must include funding adequate to provide a nurses' aide salary schedule that is competitive with local nonhealth industry workers at this skill level. Many caring individuals

are forced to seek employment providing higher hourly wages in such industries as manufacturing and food chains rather than utilizing their skills in the field of geriatric care where they were trained.

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ITEM 2. STATEMENT OF IRENE M. SMITH, EXECUTIVE DIRECTOR, HYDE PARK NEIGHBORHOOD CLUB, CHICAGO, ILL.

Senator Percy and other members of the Special Committee on Aging, the board of directors and the staff of the Hyde Park Neighborhood Club commend you on your effort to look at alternative services to nursing home care for the older citizens of our country. At the neighborhood club we believe we have a viable alternative to nursing homes by providing day care services for those elderly people who are no longer able to care for themselves during the day, but have families or friends with whom they live and can return to at night. Additionally, the day care services we plan to provide in the community will make it possible for older persons to remain in their own communities and continue the associations they have developed over a lifetime of living.

A decline in one's general health and energy level is common to all aging persons, and when this happens an older person often becomes dependent on others for providing the basic needs of daily living. If there is a family member or friend at home who can be of assistance, the elderly normally live out their lives in familiar surroundings. But if no one is at home during the day, or if an adult child would be required to stay at home in order to care for the older person, that older person may become a premature candidate for a nursing home. However, if a day care center exists which can accommodate the dependent older adult during the daytime hours and return the individual to his or her home at night, then it will be possible for that person to remain at home with family or friends who "care."

These daily supportive services—caring for personal needs, providing nutritional meals and snacks, seeing that medical and dental appointments are kept, and helping the older person to maintain social relationships with other people—can be provided in a day care center. The focus of this program will be on the enrichment and strengthening of life for the older adult—a recognition of the value of life and the contribution which the older person has made to our society.

Such a program will also emphasize the necessity of continuing to care for one's physical needs through proper nutrition and an appropriate physical fitness program geared to the needs of the elderly. In addition to activities with which the elderly are already familiar, there will be programs new to them which will stimulate them intellectually and bring them satisfaction and a renewed sense of achievement. The program we have designed will provide social work services to the client and his/her family from the time of application to the time of discharge.

Because of a minor physical impairment, or the confusion which sometimes accompanies old age, it becomes increasingly difficult for older persons to maintain their independence. A day care center will provide a comfortable, secure place in the community and the older adult may then return home at night to family or friends. Adult children will be relieved of the guilt and anxieties which often accompany the decision to place a parent in a nursing home. This program will save millions of tax dollars because the cost of day care, quite simply, is much less than nursing home care. This is a realistic alternative to nursing home care for many older people. It is a creative partnership with family and friends, which strengthens our society. We urge your committee to support the creation of day care centers for the elderly throughout the country, and furthermore, to use your influence to make title III and title XX dollars available for such programs in the Chicago area.

IRENE M. SMITH.

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ITEM 3. STATEMENT OF LYNN G. BRENNE, ACTING EXECUTIVE DIRECTOR, SUBURBAN COOK COUNTY AREA AGENCY ON AGING, CHICAGO, ILL.

The Suburban Cook County Area Agency on Aging is responsible for planning, coordinating, and administering services for the elderly with Federal and State funds that are supplemented by private funds at the local level.

Nearly 300,000 persons over 60 live in the 30 townships and 125 municipalities outside of Chicago in Cook County and these comprise the constituency of this agency. The vulnerable elderly in this population are the special concern of this

agency and are the group for whom we take our advocacy responsibilities most seriously. The Senate Special Committee's concern for alternatives to nursing homes is providing long-term care for older Americans is also ours.

The concentration of aging Americans in the age groups over 70, 75 and 80 is increasing steadily. At the same time the trend of the current generation in this country to reduce child-bearing to zero population growth will steadily diminish the extent of familial care and respect of children for aging parents that today's elderly have grown up with. The problems that these circumstances portend are here already—and they are ours.

Warehousing of disadvantaged members of our society has been both disparaged and discouraged. Some success has been achieved among the handicapped, the developmentally disabled and the mentally ill. We should do no less for our vulnerable elderly. The nursing home represents a solution of last resort. Unavoidable at times, it is nevertheless a monument to loneliness, a minimum reward to the aged, and a maximum cost to the taxpayers.

The Suburban Cook County Area Agency on Aging conducts a senior companion program which is funded by ACTION and answers a vital need. Our program services over 300 seniors in nursing homes through 60 volunteers and is heartily welcomed by nursing home providers. However, it cares for only a few of the thousands in suburban nursing homes. It should be expanded to embrace more volunteers and patients.

More important than our commitment to advocacy on behalf of persons already in nursing homes is our emphasis on senior services that will keep the elderly out of nursing homes—an objective of the Illinois Department on Aging as well. (Evidence of our common cause is described in the attached news release of September 1.) Top priority is already given through funding administered by this agency for services that enable seniors to remain in their own homes, in familiar surroundings with friends and relatives close by, where they will not be forgotten.

Several programs seek to achieve this objective and they should be consolidated to increase efficiency and reduce administrative cost and slippage. These programs include titles III and VII of the Older Americans Act and title XX of the Social Security Act. The welfare aspect of programs should be carefully separated from those services intended for the elderly generally, many of whom today are rejecting such services because they are proud, dignified, independent and resist invasion of their privacy. Only the more skillful workers can achieve acceptance with dignity and their efforts can best be monitored effectively and administered at the local level. Undue incursion of Federal and State mandate and regulation deter rather than increase the confidence and acceptance by many elderly of essential services offered in good faith.

There is no disagreement on the benefits of keeping the elderly out of nursing homes. There is however, clear choice on the assignment of responsibility for accomplishment. The 564 area agencies can best have that responsibility. The need for splintering local planning and funding distribution, the cost of redtape, and expansion of paperwork, are issues that should be met and resolved by Congress as increased appropriations for the elderly are considered.

#### [Attachment]

#### STATE FUNDS KEEP SENIORS OUT OF INSTITUTIONS

The Suburban Cook County Area Agency on Aging will soon be more active in two programs designed to help the frail elderly remain at home, with funds available under the Social Security Act through the Illinois Department on Aging.

The two programs are for adult day care and for comprehensive alternative care. Day care programs provide closely supervised activities with a lot of personal attention for small groups of seniors. Comprehensive alternative care centers provide a wide range of services that include assistance for the homebound as well as day care and other programs.

The area agency on aging is now accepting applications from local agencies to provide these services and will make recommendations to the Illinois Department on the applications received. Once programs are established, the area agency will monitor the progress of the programs, provide technical assistance, and give periodic evaluations.

Under a local effort plan, \$173,472 is available for adult day care programs in the Cook County suburbs. This arrangement requires local donors to supply 25 percent of the total funding. The remaining 75 percent comes from matching Federal funds, without any expenditure of Illinois general revenue money.

Certain applicants will receive preference for the grants. These include organizations serving areas with high concentrations of low-income and minority elderly and agencies with established day care programs or the capability to set up such programs promptly.

In suburban Cook County, \$243,000 will be awarded for a comprehensive alternative care center. The site chosen will be responsible for the coordination of at least a minimum range of services. These must include chore and homemaker services, day care, health related facilities, and counseling.

The comprehensive care program is an alternative to unnecessary and premature institutionalization. It is designed to provide a well-meshed union of programs in the area the center serves.

Many elderly individuals have needs which don't require the 24-hour setting of a long-term care facility, but do need periodic supervision, minimal assistance with personal care, and some help with home management or other services. In these cases, institutionalization can be prevented—or at least postponed—if substitute services are available in the community.

The Suburban Cook County Area Agency on Aging, through its coordination efforts in these two programs, will help to curb expensive institutionalization while assisting senior citizens to maintain their independence and dignity.

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ITEM 4. STATEMENT OF PAUL Q. PETERSON, M.D., DIRECTOR, ILLINOIS DEPARTMENT OF PUBLIC HEALTH, SPRINGFIELD, ILL.

On behalf of the Illinois Department of Public Health, I would like to express our appreciation of the effort expended by the Better Government Association and WLS-TV in their investigation. It is this sort of private commitment to independent investigation which provides valuable information on the working of the regulatory system and helps us do a better job. We will certainly consider the BGA/WLS findings in directing our activities.

There are, however, several points of clarification which we would like to raise which will make policy application of the investigation much more probable. These pertain to development of supporting data for many of the points raised in the report. We recognize the advocacy nature of this report, and would not insist on strict objectivity in reporting. However, if advocacy is to be useful, it must be supported by reliable evidence, and statements of fact must be directly related to that evidence. Otherwise, the policymaker will be unable to ascertain the reliability of the advocacy, and may adopt a course of action which will be counterproductive to all concerned.

There are three major areas in which the report could be made more useful to the State's policymaking bodies: (1) A written report of the findings; (2) quantification of the findings where possible, including both the extent and the severity of reported conditions; and (3) more specific presentation of the evidence supporting the statements of fact made in the newscast. Each of these will be discussed in turn.

(1) *Written reporting of the findings.*—Since time is limited in a newscast, only a partial discussion of findings is possible. Also, extemporaneous statements may be made which do not accurately reflect formal findings, and identification of such statements is difficult. Accordingly, we would strongly suggest that the findings of this investigation be put into writing so that they may be adequately studied and incorporated into policy. This paper should include discussion of the technical methods used in developing information, including sampling procedures used to assure that conclusions drawn from the sample will generalize to the broader group of facilities to which the conclusions will be applied. Also, the training of investigators to recognize problems (e.g., staff withholding candy from a diabetic vs. fighting with a patient to minimize food costs) should be discussed.

(2) *Quantification of findings.*—It is extremely important to document both the prevalence of reported conditions and the severity of reported conditions. For example, the report notes that 60 percent of facilities surveyed have been cited for violations of personal care standards. Does this statistic refer to isolated failures to sew a name tag on clothes, or does it refer to general neglect of patients? Either interpretation is possible, and for the sake of accuracy and public information the report should array and discuss the types of violations documented.

In terms of the extent of the findings, careful description is essential. Incidents at five facilities, of eight chosen on the basis of complaints, are noted in the report.

One appears only because of equipment failure, and one only because of an instance involving cold food. Yet the findings of the report are generalized to the industry. There are, for example, over 40 references to abuses, shocking abuses, neglect, and even killing of patients in the nursing home industry in general. Other statements also imply that the findings are general:

"Abuses and neglect continue to plague the nursing home industry." (7/17)

"Peter, you say you've placed a lot of investigators in many of these homes for a period of several weeks." (7/13)

"Many nursing homes save money by serving all three meals within an 8-hour period—but then the patient goes for 16 hours without anything to eat—or maybe a snack like a graham cracker, which they can fight over." (7/18)

"As a result, nursing homes superficially look better than they did. They may be somewhat *cleaner* than they were—they're more *modern*. However, that creates an additional problem—which is that they're more deceptive to people who are taking and putting their relatives there—they may look at a place and see that it's clean—but there might be underlying conditions which relate to *patient care*, and that's the kind of thing that we uncovered by putting people on the inside." (7/17)

"\* \* \* the State has bragged in a number of publications what they've done, about the fact that Illinois is much better because of the investigation done in 1970 by the BGA and the Chicago Tribune, and holding it up as some sort of model—and then when you go out and really look at it—you find out that it just isn't that way." (7/17)

"\* \* \* there are on the surface a lot of homes that look really nice. And that is precisely what we did on our investigation. We went to nice homes and they had a nice physical plan and so forth. But when you get into them and you look at it for a while—you find a lot of things." (7/13)

Given the constraints on air time, the investigators could hardly have presented all the evidence on which their conclusions are based. However, the entire set of evidence must be presented if their advocacy is to be useful. The policy response to the conditions reported will be very different if we are dealing with isolated incidents at five homes than it should be if conditions described in the report pervade the long-term care industry.

(3) *Evidence for statements unsupported in the transcript.*—In several places the transcript presents a conclusion without presenting the supporting evidence. It would be useful to have the supporting material made public. Such statements are made in several areas:

(a) Government misfeasance:

"Nursing home inspectors are more concerned about paperwork than people." (7/14)

"There's a lot of buck-passing between agencies regulating homes." (7/14)

"But, we have seen that agencies regulating nursing homes pass the buck and are slow to act—and often there is conflict" (7/20). In particular, "buck-passing" should be differentiated from shared responsibility. There appeared to be some confusion here, as the BGA/WLS insistence that the Department of Health, Education, and Welfare discipline facilities when the responsibility had been delegated to the city of Chicago, which, by the report's account, is maintaining current records.

"There's also a lack of obvious commitment from people in government today" (7/21). This statement is somewhat inconsistent with the massive amounts of time, interest and money devoted to long-term care—for example, the development of QES—documented in the report.

"Apparently all the regulations on all different levels of government, don't really curtail the problems in homes." 7/17

In commenting on a report published by the Illinois Department of Public Health: "You can better believe that we're going to get a list of that—that was published, and we're going to compare it to some of the inspection reports that we found" (7/17). (No report on the comparison was made.)

(b) Poor quality food:

With regard to food quality, special care should be given to documenting qualitative judgments. Consider the phrase "soup and sandwiches for a light meal" (an industry term not inconsistent with eating practices of many families) vs. "a piece of American cheese between two slices of stale bread" or "baloney sandwiches as the main course for a Sunday meal—something is definitely wrong—gentlemen." To be meaningful in challenging the industry to provide better care, the report's statements should document insufficiencies

being referred to such as infrequent delivery, purchase of commercial quality meat, etc.

Also with regard to food, the report implies that \$1.95 per person per day (\$55 per week for a family of four) is inadequate. Some documentation should be presented if this is, in fact, a criticism of the industry.

(c) Training:

"If you're in a nursing home, 90 percent of the care you receive will come from people who have no medical or professional training whatsoever. With all trends considered, and studies considered, the nursing home industry wants to keep it that way." (7/19)

Regulations require that aides receive training, including the possibility of inservice training. Evidence on the lack of any training even after employment in the facility would be important, and evidence on the general lack of training in the industry would be most helpful.

More accurately this point appears to assert that formal medical or professional training and certification is required of nurse's aides. However, given the tasks performed by these personnel, completion of nurse's aide training as required by regulations is generally recognized as completely adequate—whether the aide is working in a hospital or long-term care setting. In fact, long-term care facilities which are regarded as excellent examples of care, including those referred to by Senator Percy during this hearing, generally employ aides with this type of training.

(d) Trends in quality:

Several statements were made concluding that conditions in long-term care are, aside from cosmetic physical changes, the same as they were in 1974. (7/13, 7/17, 7/19)

Given that enormous amounts of resources have been allocated to correcting conditions, documentation of this allegation would be valuable. Of particular interest would be the frequency and severity of abuses now as opposed to 1974.

To the television news viewer, of course, these points would seem technical and unexciting and, given the media used, their omission is understandable. However, in requesting a published report which would address these and similar points we are not simply asking adherence to procedures which are generally accepted by reputable policy analysts. Policy response, if it is to be appropriate, must be based on an accurate appraisal of the scope and severity of the problems being addressed. Otherwise, government agencies may address the wrong problems or misplace emphasis. In fact, BGA/WLS report emphasizes attention to building standards at the expense of patient care—a condition which may well have arisen out of earlier reports which concentrated on fire safety deficiencies. Simply drawing attention to a problem may not be a public service if that attention is misfocused, and results in an inappropriate response.

To this point, we have concentrated on requesting clarifications and amplifications which would facilitate use of the report for policy purposes. In addition, there are several points at which the report conflicts with our understanding of the long-term care industry and its regulation:

"Statistics reveal that 71 percent of the foreign nurses taking exams in our State, flunk. *There is no systematic followup* to check if nurses continue to work as a nurse or not." (7/19)

In the long-term care industry, unlicensed personnel would be identified during routine licensure inspection surveys. Thus, failure to pass the test would prevent working as an RN for any extended period.

"There's a great deal of talk now about cost containment—the need to not raise taxes—to lower government expenditures. The decision has to be made as to whether that has to be balanced off—or can be balanced off with providing adequate care for the elderly and aged—and handicapped in our State—and that's a major policy decision—but *it isn't being discussed at any level in the government right now.*" (7/20)

In fact, this topic is being actively discussed. Governor Thompson has established a purchased care review board, composed of the directors of the major social service and health agencies and the director of the bureau of the budget, to address this and similar issues. A detailed description of the board's activities may be obtained upon request.

Also the Statewide Health Coordinating Council is developing a policy analysis of alternatives to long term institutional care, and departments of mental health and aging are pursuing development of alternatives to institutionalization as a long-term solution to rising costs.

"A team of experts from the department of mental health is there weekly, and one person stops by just about daily. Most other homes pay for private consultations—but DMH is very concerned about Glen Oaks, because one-third of its patients are from mental institutions. Their involvement is very unusual—and DMH is closely guarding a report which cites major deficiencies in the home's programs." (7/21)

It is not unusual for the department of mental health to advise facilities regarding program content, particularly after a deficiency has been documented. The report appears to be faulting an attempt to remedy a deficiency by people it has elsewhere labeled unconcerned about patient care.

Repeated comments were made in the report and in oral testimony regarding inspector's concern with physical plant. While the physical environment is important to the safety of residents, the survey format used by the State of Illinois provides a substantial portion of survey questionnaire for questions relating to patient care, including the adequacy of the diet, the appropriateness of staffing, and control over medication—the very issues raised by the report. A survey questionnaire is included for informational purposes, so that committee members may draw their own conclusions.

"During the last year, not one nursing home was closed by the Illinois Department of Public Health, and that's their style. They would rather consult than close. Enforcement of regulations could end up in the courts for years—and nursing homes can continue to operate pending lengthy litigation." (7/13)

In fact, one nursing home's license was revoked this year, but that is a minor point. Our objection is to the apparent equation of enforcement with closure. The purpose of the department is enforcement of regulation, not closing of facilities. Yet there is no mention of the number of facilities which were brought into compliance. Furthermore, compliance can usually be obtained most rapidly through citation and consulting or initiation of the hearing process, and the quickest process is, after all, in the best interest of patients. Closing of facilities leaves patients homeless and in some cases without a good substitute. In addition, the transfer trauma caused by closing will very probably cause a number of deaths as several careful studies have documented. The reporters may not be familiar with these studies.

"There's a tremendous incentive in this point count reimbursement for the homes to keep people as dependent as possible—and not to rehabilitate people who have rehabilitative potential." (7/17)

Problems with the point count are recognized. However, without some type of patient assessment tool, the same rate is applied for all patients regardless of need. Several formal studies have indicated conclusively that patient condition is an important determination of the cost of care in any type of medical institution, hospital or nursing home. That is, the sicker the patient, the more it costs to care for him. The use of an assessment tool simply permits payment commensurate with the costs of care. To do otherwise would provide a disincentive for admitting the very sick.

At the time the reimbursement system was initiated, the point count system was the only assessment tool available to us. Subsequently, we have begun development of an alternative tool which will correct the deficiencies in the current point count tool. The key here is difference between cost of care and reimbursement. That is, if it costs \$10 to care for a bedridden patient, and payment is \$10, the facility is not encouraged to keep patients debilitated but is rather being equitably compensated for the added costs of admitting a sick patient. Incidentally, despite the allegations that the current point count encourages debility, we have seen no evidence that the cost of care for the specific conditions recorded on the point count is exceeded by reimbursement, and would welcome any hard evidence that an adverse incentive does in fact exist.

These last two points seem to indicate some lack of practical experience on the part of researchers. In a simplistic sense, it would seem appropriate to close facilities which do not comply with licensing standards. Given the probability of deaths caused by transfer, the difficulty of placing patients, and the fact that more can be accomplished by consultations and hearings, massive closures are not the best alternative. Similarly, the point count system is problematic in some respects, but the alternatives are probably worse. The practicality of alternatives must be borne in mind in any criticism of present systems.

One final point to be raised concerns the reimbursement system instituted by the State of Illinois in January of 1978. At least one previous speaker indicated that the State's only objective in developing the system was minimization of its

cost. In fact, the State's goal was minimization of cost for *appropriate care*. That is, we attempted to establish a reasonable reimbursement system which was sufficient to meet the costs of good care in an efficiently run institution and in fact this system costs tens of millions of dollars above the minimum system which would have been acceptable. For example, use of the point count to adequately reimburse for difficult patients added several million dollars to our costs. An additional \$22 million was spent to assure that reimbursement for nursing care reflected the costs of facilities providing good to excellent care. In light of this, we believe this criticism of the State is unfounded.

Let me again thank the committee on behalf of the Illinois Department of Public Health for this opportunity to include our views in its hearing record. We will be pleased to respond to any questions the committee may have regarding long-term care in Illinois.

ITEM 5. STATEMENT AND ATTACHMENT OF PAT HARRISON, EXECUTIVE DIRECTOR, NORTH SHORE VISITING NURSE ASSOCIATION, KENILWORTH, ILL.

I am Pat Harrison, executive director of the North Shore Visiting Nurse Association. I am here to advise Senator Percy and the committee that there is presently existing a well-established network of organizations in the United States that provide a long-term alternative to nursing homes for the elderly, that is the Visiting Nurse Associations (VNA) which are organized on the local township and county level in many areas of the United States to give quality, low-cost home health care.

Although the VNA has no national, State, or regional organization as such, it has existed for over 80 years as independent, nonprofit local health care associations in many areas of the United States. Commonly associated with the National League for Nursing, these local organizations, under the direction of volunteer boards of directors and professional advisory committees staffed by physicians and other health care professionals, have effectively provided health care in the home. Many are licensed by the various states in which they are located and certified by both medicare and medicaid as home health service providers.

The original concept for the VNA was to provide public health nursing for indigent patients. However, today the VNA provides a wide range of health care services in the homes of all patients. Among the services given currently are skilled nursing care, physical therapy, occupational therapy, speech therapy, medical social workers, home health aides and nutrition consultants. These services are provided for fees based upon a sliding scale calculated on the patients' ability to pay. These services continue even after medicaid and medicare benefits are terminated. Greatly assisting in the funding for continuation of the home health care services for those who cannot pay are contributions by United Way, private donors, and township revenue sharing funds.

Speaking on behalf of the North Shore VNA, our area of responsibility and operations is New Trier Township and part of Northfield Township in Cook County, Ill. Within this area we provide services for the villages of Wilmette, Winnetka, Kenilworth, Glencoe, Northbrook, Northfield, and adjacent unincorporated areas. The North Shore VNA presently is the merged successor of three individual organizations formerly known as the North Shore, the Northfield, and the Wilmette Visiting Nurse Associations. The oldest, the Wilmette VNA, was formed in 1918 by a group of concerned citizens and physicians from Wilmette, Grosse Point, and Kenilworth at a time when it was determined that New Trier Township had the largest number of underweight children in the area. In 1920 the Chicago Tuberculosis Institute became interested in the project and assisted in enlarging the scope of care given so that adults as well as children could be aided in health problems. Subsequently, various churches, school boards, the village of Wilmette, New Trier Township, and the Wilmette community chest contributed to fund the services provided, which included assistance in public immunization programs. Since 1918 the North Shore VNA has provided 60 years of continuous home health care services.

In conclusion, I would like to stress that one of the prime goals of our organization is to give quality, low-cost health care for the elderly in their homes. The VNA has proven that this is feasible, practical, and desirable. I have brought with me a recent article that I wish to give you and ask that it be included in the record of this hearing. It is entitled "Home Health Care: Services and Cost," published in *Nursing Outlook* in August of this year. This article summarizes findings that document types of services needed to maintain chronically ill patients at home and the modest costs associated with such services.

Our headquarters is located at 509 Park Drive, Kenilworth, Ill. 60043 (Telephone: 312-251-0660). Should the committee desire further information about our operations and the community needs serviced by our organization, I would be happy to respond.

[Attachment]

### HOME HEALTH CARE: SERVICES AND COST

(By Geraldine Widmer, Roberta Brill, and Adele Schlosser)

Recent concern about the increasing costs of health care has directed attention to an established, but still underused, alternative—the home, an institution in its own right. There have been many reports documenting the extraordinary costs of institutional care, as well as the inappropriate use of nursing homes and long-term care facilities. While some articles have been written postulating the cost effectiveness of care at home and the barriers to expansion of home care services, and studies have been made on limited aspects of home care or specific home care populations, little objective data are available to determine the total costs of home care services, how they are used, and how they are reimbursed.

In a unique partnership, the Visiting Nurse Service of New York and the New York City Health Systems Agency conducted a study of home care during 1975-76 in one district of New York. The study, which was funded by the regional medical program, had three major objectives: (1) to obtain information about patients needing home health care and their utilization of home health care services when all barriers to services, such as cost, were removed; (2) to arrive at a reasonably accurate estimate of the cost to the patient and to third party payors of the services needed to maintain the patient at home; and (3) to obtain information about the types and amounts of reimbursement now available to defray the costs.

Although the study deals with services in one urban setting, we believe the findings have significance for planners, health care providers, and legislators concerned with a health care delivery system that is both economical and responsive to changing population needs.

#### PROJECT DESIGN

In designing the study, we took into consideration the major factors that inhibit the expansion of home health services: the lack of payment for large segments of the population and for necessary services, lack of data about relative costs of care for the same services rendered in different settings, and information about costs per patient that would guide planners, administrators, and reimbursers to anticipate home health care expenditures. This study was, therefore, designed to elicit needed cost and reimbursement information in a way that would have applicability to a community-based home health care program or to a multipurpose health care system. In order to test the utilization of a broad range of home health services, the study was set up as a demonstration project, in which funds were made available for an expanded range of home health services for dependent, chronically ill patients for whom there otherwise would have been no source of reimbursement.

A community-based home health agency was used as the service delivery model because of its applicability in other parts of the United States. The Visiting Nurse Service of New York (VNSNY) is a voluntary agency, certified for medicare and medicaid reimbursement, licensed by New York State, and accredited by the National League of Nursing and the American Public Health Association. During 1975, the first year of the project, the VNSNY staff cared for 50,000 patients in three of the city's boroughs—Bronx, Manhattan, and Queens. In common with other community-based agencies, VNSNY has the organizational and administrative independence to care for a diversified patient population.

The site selected for the study was a sub area of a VNSNY district located in the Northwest Bronx, chosen because it has a high concentration of people over 65 years of age—19 percent as compared with 12 percent citywide. In addition, the population represents a range of economic groups, thus providing an opportunity to observe the different cost and reimbursement experiences of a variety of clients.

#### SERVICES PROVIDED

The services offered patients included the customary ones provided by VNSNY—nursing care, home health aides for up to 24 hours a day, physical therapy, speech therapy, social work services, medical consultation, nutrition consultation—as

well as several new services to make the range more complete. These new services included increased availability of a physician for consultation and visits, medical supplies and equipment, laboratory and diagnostic services, and transportation by ambulance, ambulette, and taxi for health-related purposes. If no payment was available either from the patient or through third-party payors for these necessary services, project funds were used. Otherwise, all customary billing and administrative services were used.

As part of the project design, staff nurses of the VNSNY assumed a greater role in coordinating all services for patients on home care. They coordinated all medical and social services provided by and through the home health agency. Each nurse developed the patient care plan and scheduled the frequency of visits. The nurse remained in contact with the patient's referral source, and determined, in conjunction with the physician, when to discharge the patient.

Patients admitted to the project were typical of the bulk of a home health agency's caseload. All were chronically ill, requiring nursing care, household management and other aspects of long-term care. Patients were admitted regardless of availability of reimbursement, referral source, medical supervision, or prior institutional experience.

To publicize the project, the project staff met with community groups and hospital personnel and sent information to local physicians to stimulate referrals and to reach new groups of patients who might otherwise have been referred to institutions.

#### ADMISSION AND ASSESSMENT

All referrals to the VNSNY study district were evaluated for possible inclusion in the study. Patients were phased into the project at a rate of approximately 45 per month over a 15-month period from January 1975 through March 1976.

On admission to and discharge from the project, the nurse completed a patient assessment, which was based on DHEW's patient classification form, and included selected sociodemographic and physical status information. The sociodemographic data included age, sex, health area, marital status, and presence of others in household. Physical status information included diagnosis; acuity of physical faculties, such as sight and hearing; and ability to perform twelve necessary activities of daily living—mobility, walking, eating, dressing, grooming, bathing, transferring, wheeling, stair climbing, toileting—bowel and bladder habits—and housekeeping and marketing chores. The nurses noted which areas the patient could do alone or with assistance and the type of assistance needed. In addition, the patient's referral source, medical supervision, and available source of payment for care were recorded.

The patient's ability to perform essential daily activities was coded under one of three primary functional groups:

(1) Group I—Patient requires assistance of another person to perform household and marketing activities. Does not require assistance with any other activities of daily living.

(2) Group II—Patient requires assistance of another person to perform one or more activities of daily living, household and marketing tasks.

(3) Group III—Patient entirely dependent on another person to have performed for him one or more activities of daily living, household and marketing activities.

It should be noted that these are *physical* functional categories. The degree of mental impairment in any of the three is reflected only to the extent that ability to perform activities of daily living is diminished by emotional causes. Patients were evaluated as to their behavior, that is, withdrawn or abusive, and their orientation; however, no meaningful way of incorporating these ratings into the functional groups was devised.

#### TYPES OF CHARGES

The total cost of home health care included all charges for services within and "outside" the program utilized while the patient was under the care of the VNS and the method of reimbursement for each. Although prescription drugs were a part of the overall cost, these expenditures were excluded from the study because it was difficult to obtain accurate and complete data. Hospital stays that may have occurred during a course of care were also excluded, since the usual policy of home health agencies is to discharge patients when they are hospitalized and to readmit them if they need care following their hospitalization.

Information about services received from sources other than VNS was obtained primarily through monthly interviews with patients or their families. These

services included visits to hospital clinics, physicians and medical specialists, physical therapists, speech therapists, social workers, special therapists, as well as supplies and equipment, laboratory services, and transportation to health care providers. Dental services were excluded because only two patients of the first 250 reported using them.

This information was recorded on a monthly interview form, similar to that which was used in the 1966 nationwide medicare survey. At the same time, a monthly diary of services used was kept by each patient. In most cases, patients had little difficulty recalling the types of services they used; however, they had problems remembering the charges for these services and the amounts reimbursed. Often the provider or third-party payor had to be contacted for this information.

#### CHARACTERISTICS OF CLIENTS

A total of 420 chronically ill patients, 134 men and 286 women, completed a full period of care or were admitted during the 15 months of the study. Their ages ranged from 21 to 100 years, with a mean age of 72 years. Nearly 80 percent of the patients were over 65 years of age; almost 50 percent were 75 years or over, and 13 percent were 85 years of age and older. Women not only outnumbered men patients two to one, but also tended to be older. Approximately one-third of the patients lived alone—40 percent of the women, compared with 16 percent of the males. Their ethnic background reflected that found in the study areas' general population: nearly 93 percent of the study group was white, blacks comprised 3 percent, Hispanics 3 percent, and Orientals the remaining 1 percent.

Patients frequently had multiple diagnoses of varying impact and severity. Based on their primary diagnosis, however—that is, the condition responsible for the major aspects of home health care—heart conditions and malignant neoplasms were the most frequently reported diagnoses (19 percent and 14 percent respectively), with diabetes, fractures, and CVA's the next three most frequent. In addition, many patients had physical impairments common to advancing age. Vision problems were reported by 69 percent, hearing problems by 26 percent and speech problems by 14 percent.

The study population was well represented in each of the three physical function groups, with 39 percent in Group I, 28 percent in Group II, and 33 percent in Group III. As would be expected, age was an important factor in the patient's ability to perform activities of daily living, and people living alone tended to function more independently.

Acute care hospitals accounted for the largest number of referrals (46 percent) with nearly three-fifths of these referrals from inpatient services, one-fifth from outpatient departments, and one-fifth from the home care departments. Private physicians referred nearly 20 percent of the total; these were patients with no immediate prior hospitalization. Fifteen percent of all referrals came from community health and social agencies; the patient or his family initiated 11 percent; and skilled nursing homes and health-related facilities accounted for the remaining 9 percent.

Less than 6 percent of the patients reported they had no medical supervision on admission to the project. The majority of patients (72 percent) were under the care of a private physician. Twenty-one percent of the patients used the hospital outpatient department or emergency room for their medical supervision.

Nearly all patients (96 percent) reported having some insurance or third-party coverage for medical expenses. Forty-four percent had only medicare; an additional 26 percent had medicare in various combinations with medicaid or private insurance; 29 percent of the patients, two-thirds of whom were under 65, had only medicaid or medicaid plus supplementary coverage; an additional 7 percent had other types of private insurance.

One-half of the study patients were discharged from the home health program because either the patient's condition had improved to the point where nursing care was no longer required or the patient and/or family and friends assumed responsibility for his care. An additional 25 percent were admitted to inpatient facilities and 4 percent of the patients died.

In comparing categories of patients, it was noted that 63 percent of those who lived alone no longer needed care, as compared with 49 percent of those who lived with others. This outcome, an apparent function of a greater degree of physical impairment among those living with others, is also found with regard to hospital admission: 28 percent of those living with others had to be admitted for inpatient care, as compared with 21 percent of those living alone.

## NURSING AND SPECIALTY SERVICES

The range of nursing services included health education, monitoring of vital signs, providing medically indicated treatments, performing personal care activities, coordinating all health services, and supervising paraprofessionals. The nurse, who can perform all of these activities, is the focal point of patient care, since coordination and supervision are especially significant components of home health care. In addition, two types of aide service were provided: staff VNS aides who were assigned to patients for up to two-hour periods to give selected treatments and other aspects of personal care, and aides obtained through contracts with homemaker agencies whose assignments were for longer periods (4 to 24 hours) and who provided combined personal and environmental care. Housekeepers were assigned or included in the study only when nurses found that their services were needed for health-related reasons.

The average number of nursing visits per patient was 8.5. In addition, 10 percent of the patient population received visits of up to 2 hours at a time from staff aides, who averaged 17.3 visits per patient. Nearly two-fifths of the patients had some type of housekeeper or personal attendant services, whether they were provided through the program or obtained from outside sources. These patients needed an average of 313.6 hours or 39.2 eight-hour days of this kind of support service.

More than two-thirds of all patients saw a physician and these patients averaged 2.1 visits each. Those patients age 65 to 74 used physician services the most. A physical therapist treated 33 percent of all patients, with each patient receiving an average of 1.8 visits. Use of this specialty was higher in the younger age group.

Slightly less than 16 percent of the patients received the services of social workers and this averaged 2.3 visits for each patient. However, people who lived alone and received social work visits averaged one visit more than people who lived with others. This finding reflected the role played by the social worker in helping a patient with medically-related problems in getting insurance coverage and qualifying for SSI or Medicaid.

Four percent of the patient population received speech therapy, which averaged 5.3 visits per patients. Four percent also required other special therapies, including dialysis, chemotherapy, and radiotherapy. Patients in this group made an average of 8.1 trips for these therapies.

Other supportive services included transportation, medical supplies, and laboratory services. Because transportation was used primarily to get patients to and from medical appointments, utilization was highest (44 percent) in the 65-74 age group, consistent with their greater use of physician services.

Over two-fifths, 45 percent, of the patients were provided with medical equipment or supplies. More of the patients aged 65-74 received this service than did those under 65 or over 74—52 percent compared to 41 percent and 42 percent, respectively. Laboratory services were used by 16 percent of all patients, with an average of 1.2 times per patient.

## LENGTH OF STAY

The average length of stay of all patients in the program was 52.4 days. This figure refutes the common perception that patients receiving home health services need lengthy or, in some instances, lifetime care. While all study patients met the eligibility criterion of chronic illness, some required only short-term post-surgical care, and others needed care and teaching only for a transition period while they learned to care for themselves. Still others required fairly lengthy, ongoing maintenance care. As a result, some patients were under care for several days, while others were still under care when the study ended. Since 74 percent of all study patients had only one admission in a year's time, this means that most patients required home health services for less than 2 months out of the year.

Which functional group the patient was in appeared to be the single best indicator of length of stay. The most functionally disabled patients had the most number of average days in the program—54.90, and the least disabled group had the fewest days, 46.25. Patients under age 64 years had an average care period nearly 10 days longer than those 65 and older. Younger patients requiring home care for chronic conditions may be sicker than their older counterparts, or may be in an earlier phase of accommodating to chronic illness and, therefore, need more assistance. Patients who lived alone had a longer care period, 56.6 days, than those who lived with others, 48.5.

Only 20 percent of the patients were readmitted for home care within a year of their first admission. Of these, 16.9 percent had two admissions during the year, 2.6 had three admissions, and 1.3 percent had four admissions. The 43 patients who reentered the project for a second admission showed some differences when compared to the group who had experienced only one admission. The second admission group had more men (44 percent compared to 32 percent women), and had a higher percent of more functionally dependent persons (38 percent compared to 33 percent). Thirty-seven percent of this group were discharged to hospitals following their first home care admission, as compared to 26 percent of those with only one home care admission. The average length of stay within the program for a second admission was higher than for a first, 64.8 compared to 52.4 days.

#### COSTS OF THE SERVICES

The mean cost (based on fees charged) for all health care services received by the patient population during their first admission was \$765 per case, or \$14.71 per day. The median case cost was \$347. The dramatic difference between mean and median costs indicates that costs were not symmetrically distributed. A special attempt was made to identify which population subgroup and particular service use pattern was causing the average cost to be so unrepresentative of the experience of the population as a whole. When the population was ranked from lowest to highest according to each patient's total costs and divided into ten equal groups, an important finding was made. Ten percent of the population incurred almost 47 percent of the costs; the combined ninth and tenth groups incurred 67 percent of the costs.

When patients in the tenth group (highest cost) were compared to all other patients, no substantial differences were noted in age or presence of others in the household; however, there was a marked difference in their physical functioning. In this group, twice the number (62 percent) of persons were in functional Group III, compared to the rest of the population (31 percent). In fact, one-fifth of all persons who were least capable of carrying out activities of daily living (Group III) were in the tenth group. The increase in cost with each decile did not reflect a uniform increase in the utilization of all services. The main increase in cost was attributable to the use of home health aides, personal care services, and household employees.

The average total cost for the population, excluding the tenth group, was \$453; whereas, for the tenth group alone, it was \$3,744. The major factor contributing to the high cost of this group was a very long length of stay—149.7 days as compared to an average of 52.4 days for the study group as a whole. The per diem costs for the group were also higher—\$25.01 a day, compared to the overall average of \$14.71 per day. The level of disability of this patient group, as evidenced by their physical functioning and dependence on household and personal care support services, indicates that these patients might require institutional care at a higher and therefore more costly level if home care services were not available to them.

For the study population as a whole, personal care and household support services accounted for the largest single item of the total home health expenditures. Services provided by a nurse made up 30 percent of the total costs; physician visits amounted to 7 percent of the total; equipment and supplies, 5 percent. Each of the remaining services accounted for no more than 3 percent of the costs.

Average costs showed little variation by age or living arrangement, however, there was a marked difference in costs by functional group. Per diem costs were \$11 for Group I, \$15 for Group II, and \$20 for Group III. This demonstrated again that as functional ability decreased, the need for services increased.

The average total cost for health services for a second admission was higher than that for a first admission, \$848.66 compared to \$768.80; however, the average per diem cost was less because of the longer second admission stay, \$13.51 compared to \$14.71.

#### PAYMENT FOR HOME CARE

Despite the fact that 96 percent of the patients reported some third-party coverage on admission, one-third of all home care costs were not reimbursed by any third-party payor. While nearly 80 percent of the patients were over 65 years of age and therefore eligible for medicare benefits, this insurance program covered only one-fourth of the total costs. In addition, the study revealed that nearly one-half of the total home health expenditures were made for "out-of-program" services, that is, those not provided by the VNS. This often meant that patients and families had to arrange and, in many instances, pay for the service themselves. Variations, however, occurred in coverage of individual services: Less than 30 percent of physician fees and only 16 percent of the cost of nursing were not reim-

bursed. In contrast, 43 percent of housekeeping and home attendant costs were not reimbursed; these services comprised 41 percent of all non-reimbursed costs.

#### CONCLUSIONS

Certain findings of this study appear to have considerable significance from the standpoints both of delivery and reimbursement of home health services. The study documents the value of home health care and refutes some of the misconceptions which have prevented or slowed expansion of such services. For example, the data on length of stay belie the concern often expressed that home health services deal primarily with a population needing long-term, if not life-time care. The patients in this study were all chronically ill, the vast majority elderly, many were living alone, and one third were so dependent as to be at the level of care provided in a skilled nursing facility. Yet the average length of stay was less than two months. Again, in contradiction to the frequently expressed concern that care of the chronically ill at home involves inordinate numbers of expensive professional personnel, the study findings reveal a modest use of the professional worker. Utilization patterns, in fact, show that the professional nurse was very appropriately used as coordinator and manager of care, with the direct services provided by less costly personal care workers, such as home health aides and housekeepers. Use of other supportive services, such as transportation, housekeeper services, and medical supplies and equipment, was also extensive.

The importance of the patient's level of functional ability rather than diagnostic classification emphasizes the need to develop a full range of services to meet the requirements of patients in various stages of illness. The increased use of "out-of-program" services leaves no doubt that a complete range of services must be provided in order to establish home health agencies as true health care institutions. It is unconscionable to expect patients and families, already burdened by the concerns and costs of chronic illness, to arrange and/or cover the costs of half the services that are needed. The alternate, of course, is more costly institutional care.

This fact is all the more striking if the median cost of \$347 per patient in this study is compared with what the costs of care for these patients would have been in institutions. For example, at the time of the study, the monthly cost for institutional care were \$1,380 per patient in a skilled nursing facility and \$857 in a health-related facility. The fact that only 10 percent of the population incurred almost half the costs lends further weight to the significance of functional abilities in planning and providing health care, and the urgency of predicting the levels of care needed.

Another significant finding was that one-third of all costs were not reimbursed by any third-party payor. This high proportion of unreimbursed services is especially surprising in view of the fact that less than 4 percent of the patients reported not having some third-party coverage for health care on admission. Although 80 percent of the population had medicare coverage, the relatively minor role played by medicare in covering these patients' health care costs further documents medicare's focus on short-term acute conditions, rather than on the more realistic services required by the covered population.

In conclusion, based on the findings of this study of home care needs, we believe that:

- (1) Care at home should be considered before all other alternatives. With careful professional assessment regarding functional ability and level of care, chronically ill patients can be cared for at home at lower cost than in institutions.
- (2) Home health agencies must expand their own services and move to coordinate support services in order to become effective health care institutions.
- (3) Legislators must be helped to understand the relationship of functional levels of care to costs. Home health agencies should be encouraged to develop varied charge structures for different levels of care and units of care with full accountability for effective utilization of personnel and services.
- (4) Legislators must be helped to review and correct some of the restrictions on service which limit the types and amounts of assistance available to patients at home.

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ITEM 6. LETTER FROM JEAN R. CLELAND, NORTH SHORE SENIOR CENTER, WINNETKA, ILL., TO SENATOR CHARLES H. PERCY, DATED SEPTEMBER 8, 1978

DEAR SENATOR PERCY: I attended the Senate Special Committee on Aging hearing held in Chicago on August 30. There are some points I would like to make in addition to the testimony given that day. Your Chicago office has told me this letter will be incorporated into the record for the day.

First, I am dismayed at what I presume to be a general practice in Illinois nursing homes of reticence regarding the "circuit breaker" and "additional tax grant" benefits to which many residents are entitled. Many older people still don't know about these benefits, especially if they have been institutionalized for some time; yet they are often eligible for them. Even persons on medicaid are entitled to the additional grant portion and, according to a recent ruling by the department of public aid, are not obliged to turn this windfall over to the department. Nursing homes either don't have the staff or the will to help residents file for these grants, though the few extra dollars would make life a bit sweeter for these people. I fear that nursing homes across the country are similarly negligent in helping their residents take advantage of benefits available in their localities.

Second, though day care centers and home health care programs were generally supported in the hearing, I heard nothing about the concept of congregate housing services which have received recent support with the passage in the Senate of S. 3084 and, in the House, of H.R. 12433. This kind of option is a very attractive alternative to nursing home institutionalization for those who can no longer be fully independent. Senator Frank Church says that 30 percent of the residents of nursing homes do not need to be in them. If home health care programs were broadened to subsidize the minimal services required by congregate housing residents, and section 8 similarly extended to cover such housing, some of that population that is now unnecessarily confined to nursing homes could have happier, more appropriate living arrangements.

Third, we hear again and again of persons who have to use up their life savings to pay for long-term confinement in nursing homes at the intermediate care or sheltered care levels. We believe that medicare should be expanded to cover persons who must be institutionalized but who may not need skilled nursing care.

Finally, you asked whether there is any source of information in the Chicago area providing ratings or objective evaluations of nursing homes. I believe there is none. Yet, at this agency, our counseling staff spends a great deal of its time assisting people in making appropriate decisions about the choice of nursing homes, though we never actually recommend one. We can provide a client with a considerable amount of factual information about a whole range of homes in the north suburban area, plus some useful criteria about the way to go about choosing one. Even the Department of Health, Education, and Welfare puts out a useful guide which I found not long ago in the giveaway rack at the local A&P! So there is help available for the consumer who is fortunate enough to be in touch with a place like this. Even so, I believe we need some tool which measures quality of care so that the general public can know what it is buying.

Yours very truly,

JEAN R. CLELAND.

ITEM 7. LETTER FROM DR. BERNARD D. PERLOW, PRESIDENT, BELMONT REST HOME, INC., CHICAGO, ILL., TO SENATOR CHARLES H. PERCY, DATED SEPTEMBER 14, 1978

DEAR SENATOR PERCY: Upon my return to Chicago on September 4, 1978, there had been brought to my attention newspaper reports of the hearing held under your chairmanship on August 30, 1978, in Chicago, Ill. This hearing was intended to deal with the issues of governmental regulations and of alternatives to institutional care. According to the newspaper reports allegations were then made by representatives of the Better Government Association against the Belmont Rest Home, and these allegations were prominently publicized by the media. As president of the Belmont Rest Home, Inc., I should like to have the following statements included in the hearing record:

(1) The statements made by Better Government Association and media representatives, as publicized, were incorrect, inaccurate, and misleading with respect to the Belmont Rest Home.

(2) Such statements and inferences drawn therefrom constituted in essence unwarranted allegations drawn from improper and possibly illegal intrusions as well as the invasion of private and patient rights by agents of the Better Government Association and/or the media.

(3) The scope of the testimony taken, as reflected within media excerpts, was beyond the announced purpose and purview of the hearing, and the publicity generated thereby caused detriment to the Belmont Rest Home and its owners by airing and republishing unsupported allegations.

(4) The Belmont Rest Home has made and continues to make every effort to comply with all applicable regulations of all governmental bodies with which it is involved.

(5) The Belmont Rest Home has been throughout the years of its operation under the present ownership dedicated to quality patient care and has been deeply concerned with the welfare and well-being of its residents.

Respectfully yours,

DR. BERNARD D. PERLOW.

ITEM 8. LETTER FROM MARK PICK, ADMINISTRATOR, BALLARD NURSING CENTER, DES PLAINES, ILL., TO LAWRENCE GRISHAM, LEGISLATIVE ASSISTANT TO SENATOR CHARLES H. PERCY, DATED SEPTEMBER 14, 1978

DEAR MR. GRISHAM: We are informed that on August 30, 1978, a hearing was held dealing with the issues of governmental regulations in the institutional health care industry and dealing with alternatives to institutional care. We agree that these areas, as well as all other areas which might lead to the attainment of the highest standard of care possible, are proper topics of concern. We do, however, feel that facilities that do meet the needs of elderly citizens and others in need of institutional care should not properly be tainted by specific and unsupported allegations made and publicized within such a hearing.

Although beyond the stated scope of the Senate hearing, our facility, Ballard Nursing Center, 9300 Ballard Road, Des Plaines, Ill., was the subject of testimony alleging poor and inadequate care. We strongly disagree with the allegations and innuendos within such testimony and within the WLS-TV/BGA report involving our facility, as the factual statements were inaccurate and misleading and were based on an improper method of gathering information.

We are informed by numerous residents of our facility, their families, and health care professionals in our community of the feeling that Ballard Nursing Center does provide quality care in a compassionate manner with foremost regard for the patient/resident's dignity.

We have always made, and will continue to make, every effort to comply with all rules and regulations governing long term care, and will always advocate and maintain the delivery of the highest level of care attainable.

Respectfully submitted,

MARK PICK.

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