

HOME HEALTH CARE: FUTURE POLICY

JOINT HEARING
BEFORE THE
COMMITTEE ON
LABOR AND HUMAN RESOURCES
AND THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
NINETY-SIXTH CONGRESS
SECOND SESSION

ON

EVALUATION OF FEDERAL POLICY, PROGRAM ADMINISTRATION, THE DELIVERY OF SERVICES IN COMMUNITY PROGRAMS, AND THOSE WHO WORK TO SERVE THE REAL NEEDS OF ELDERLY AND DISABLED PERSONS

NOVEMBER 23, 1980

PRINCETON, N.J.



Printed for the use of the Committee on Labor and Human Resources
and the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE
WASHINGTON: 1981

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HOME HEALTH CARE: FUTURE POLICY

SUNDAY, NOVEMBER 23, 1980

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES
AND SPECIAL COMMITTEE ON AGING,
Princeton, N.J.

The committee met, pursuant to notice, at 2:05 p.m., in rooms A and B, at the Julius A. Rippel Education Center for Health Affairs, 760 Alexander Road, Princeton, N.J., Senator Harrison A. Williams, Jr. (chairman of the Committee on Labor and Human Resources) presiding.

Present: Senators Williams and Bradley.

The CHAIRMAN. Good afternoon to all of you.

We now begin 2 days of discussion to focus attention on home health care needs and other aspects of the same objective—the objective of making it possible for older people to remain as independent in their lives as possible and to avoid the necessity of institutionalization whenever possible.

This is an unusual hearing that Senator Bradley and I are conducting here from our respective committees. It is unusual to have a Sunday hearing of Senate committees. I believe that no subject matter lends itself more perfectly to the day than our concern for the individual needs of those who we address when we talk about home health care for the elderly and the disabled.

From the Committee on Labor and Human Resources, where I am the chairman, and from the Special Committee on Aging, where Senator Bradley is a member, we are coming here today with gratitude to all of you who will be participating and giving us, from your experience, the information that we can use to build our Federal legislative effort. All of you have devoted yourselves to the needs of human beings in situations where they require attention at home with health care services.

This begins 2 days of activity in Princeton. This hearing today and the State conference that the Governor has called for tomorrow all had its genesis about a year ago when people from the Home Health Agency Assembly of New Jersey came to Washington and worked with our Labor and Human Resources Committee addressing the need for bringing together the best thought, background, and experience to develop a new comprehensive response for home health care needs from a policy that is now fragmented and beset with so many problems.

I am going to put my more formalized statement in the record. We are creating a record here that will be a bible for legislators, I am sure, when we work on the legislative proposals before us in Congress. This hearing, together with much of tomorrow's activi-

ties, will become a record that will be part of our congressional deliberations.

[The opening statement of Senator Williams follows:]

OPENING STATEMENT OF SENATOR WILLIAMS

The CHAIRMAN. It is a pleasure for me to convene this hearing, together with Senator Bradley, on the issue of home health care and future implications for public policy. This is a joint committee hearing between the Senate Committee on Labor and Human Resources and the Senate Special Committee on Aging.

We will hear testimony from a variety of distinguished witnesses involved in the evaluation of Federal policy, program administration, the delivery of services in community programs, and those who, everyday, work to serve the real needs of elderly and disabled persons.

The urgent need to revise and expand home health care programs has begun, finally, to gain the recognition in Congress that we have sought for many years. A number of legislative proposals were introduced in the current session of Congress, one of which I cosponsored with Senator Bradley to amend the Social Security Act to provide a noninstitutional program of community based long-term care services for the elderly and the disabled.

This legislation and similar proposals in the Senate and House of Representatives have generated a broad discussion over the issues of home health care and the alternatives that should be debated in the next Congress.

This hearing will provide the Senate with basic information necessary for determining the impact of home health care needs on future policy.

The hearing was convened today to coincide with the Governor's statewide conference on the same issue. The issue is an important one for New Jersey, and I want to commend the Governor for sponsoring such a conference.

At the conclusion of today's hearing, we will leave the committees' record open to accept additional statements that the witnesses or other concerned individuals wish to make. We also will make arrangements to incorporate the proceedings of the Governor's conference into our hearing record, so that the Congress and the public may have the benefit of that discussion as well.

During the past decade, experts in the field of aging and long-term care have stressed the importance of providing alternatives to needless institutionalization for the elderly. By providing help with medical attention or personal care such as meals and housekeeping, we might be able to give many seniors a chance to continue living in their own dwellings rather than relying on institutional care.

As the proportion of older Americans in the United States continues to grow in the coming decade, the issue of home health care and in-home services will become much more important and our response will have to be much more direct and complete.

We must make available a wider range of home health care and long-term care options to persons at risk of entering and institution. We must continue to seek a comprehensive range of services

to meet individuals' various needs and to develop better methods for funding and reimbursement.

Some of the alternatives to the current system may include: Adult day care, where a wider range of health care services are provided on a daily basis in a day care center; home-health care, where homemakers provide assistance with daily household chores and nutrition services; foster care, where an older person lives with and is cared for by a family or individual; and home-delivered meals.

The benefits available through medicare and medicaid only cover a small portion of the services usually needed to make home care a viable option. The Older Americans Act provides the assistance necessary for nutrition programs and social services, but often cannot fully serve in-home health needs.

The testimony we will hear today is an important first step in discussing the problems and alternatives that should be considered in developing a more comprehensive approach to home health care policy.

[End of opening statement.]

The CHAIRMAN. So, Senator Bradley, I know that we share the importance of what we're about today. I welcome your statement.

Senator BRADLEY. I would like to thank Senator Williams for his kind words and say that as a member of the Aging Committee, I replaced Senator Williams who was on that committee for a long time. I have a big job in trying to follow in his footsteps because he has left a record that, in some sense, is unparalleled in legislation that affects and assists older Americans in this country.

I think during the next 2 days we will have a chance to benefit from hearing from real experts in the area of home health care. I would point out that it is not just the Aging and Labor and Human Resources Committees here but also the Finance Committee, of which I am a member, that will benefit from these deliberations.

The bill that I have introduced, along with Senator Packwood and Senator Williams, has been referred to the Finance Committee. It is called the Noninstitutional Long Term Care Services for the Elderly and Disabled Act—someone has to think of a quick short word with all those initials—and is, I think, a very important development.

It consolidates a lot of the programs that are now aiding senior citizens, widens the range of in-home services, provides tax credits, and also provides a way for screening and assessing the needs of elderly Americans so services can be delivered in their homes.

I would like to reemphasize what Senator Williams said: that there is movement on this issue on a broad front in the Senate where the Packwood-Bradley bill is before the Finance Committee, and also where next year the Older Americans Act will be up for renewal.

Since the Older Americans Act was largely written by Senator Williams, I am sure that he will have a large role in shaping the renewal legislation. Legislation similar to our home care bill has also been introduced in the House. Even with the change in administration, I think there is a growing interest on the part of the Reagan administration in home health care.

Tomorrow we will all be participating in the New Jersey Conference on Home Health Care. I would like to remind everyone that next year there will be the White House Conference on Aging, which will offer another opportunity to focus on the home health care issue.

I hope that these hearings today will help us examine a range of issues in the home health care field, including when and how home health care can be an appropriate substitute for nursing home care and what will be the cost impact of the changes in Federal and State programs which will be necessary in developing a comprehensive home care program.

I would submit the rest of my prepared statement for the record and thank the chairman again for his willingness to invite me to participate in these hearings today.

[The prepared statement of Senator Bradley follows:]

PREPARED STATEMENT OF SENATOR BRADLEY

Senator BRADLEY. I see this hearing, and tomorrow's conference on future options for home health care policy, as a very important opportunity for the U.S. Senate to hear from some of the real experts in home health. I say "real" because I know that most of the activity in home health is here at the State level.

We have depended on you in the past, and will continue to depend on you, to help us in the Congress frame the issues and make the necessary decisions to arrive at a comprehensive national policy in home health care.

As most of you know, we have had a somewhat difficult road in home health care policy in recent years. There have been numerous hearings and task force reports—all presenting in rather startling statistics the spiraling costs of institutional care and the incidence of unmet need for home health services among our elderly and disabled population. Yet we are still trying to get some very basic and long overdue amendments to the medicare home health program through the Congress.

But I think all of us—at all levels of government and in the Congress—are now entering an exciting time for home health. We all have an opportunity, and a responsibility, to participate in shaping a new, national, comprehensive policy on long-term care—a policy with a system of community, rather than institutional, medical and social services as its cornerstone.

That is the thrust of a bill Senator Williams and I recently introduced in the Senate—S. 2809, the Noninstitutional Long Term Care Services for the Elderly and Disabled Act. The bill would consolidate the existing home care services now financed by medicare, medicaid, and title XX under a new title—title XXI—of the Social Security Act. It would make available a broader range of home care services for all elderly and disabled—including homemaker, home health care, adult day care, and respite care—and would provide a tax credit of \$100 per year to families caring for dependent elderly relatives. Funding for screening, assessment, and case management would also be provided in order to insure that those at risk of entering a nursing home would be able to make use of home health services as an alternative, if appropriate.

This bill represents an ambitious and far-reaching proposal to expand and change the entire system of publicly funded home care services. It will undergo modifications, and we have already begun hearings for this purpose in the Senate Finance Committee. But I am convinced that this legislation moves us in the right direction.

What is encouraging in the present situation is that our bill is not the only piece of legislation and our hearings not the only forum for discussion of long-term care needs and priorities. First, another bill with similar purposes has been introduced in the House of Representatives by Congressmen Waxman and Pepper. This bill, H.R. 6194, would make some immediate changes in Medicaid to lessen the bias toward funding services primarily in institutional settings and would encourage States to expand the range of home care services reimbursed by Medicaid.

In recent months I have also seen a greater sense of urgency in the policy debate and some new funding initiatives on home health policy within the Department of Health and Human Services. We will have the opportunity to hear about these developments from a representative of the Undersecretary's task force on long-term care this afternoon.

Even with the upcoming change in administrations in Washington, it appears that the development of long-term care and home health policy is one issue which will not disappear. I was interested to see that some of the earliest press leaks from the new Reagan policy advisors included statements urging the White House to consider initiatives in home health care.

Perhaps one of the most encouraging signs of all represented by the New Jersey Conference on Home Health Care which will open here this evening. Only relatively recently have policymakers from all aspects of health services and social services, as well as higher education, come together to debate issues in home health. This gathering of professionals from a range of disciplines alone is an indication of the magnitude of the policy changes which need to be made in our fragmented system.

The upcoming White House Conference on Aging offers us another opportunity to move this process along. Long-term care policy will be a major focus, and a miniconference on long-term care, convening next month, will have representation from a very broad range of policymakers.

I hope this hearing will include a full examination of a range of home care issues, including when and how home care can be an appropriate substitute for nursing home care, and what will be the cost impact of major changes to Federal and State programs. We actually have three Senate Committees with a strong interest in home health represented here, with Senator Williams chairing the Committee on Labor and Human Resources while I am a member of the Finance as well as the Aging Committee. I know that both of us are looking forward to hearing concrete suggestions for different approaches to providing home-based care to the elderly and disabled, as well as improvements to existing legislation. Our panel of witnesses today are uniquely qualified for this job.

The CHAIRMAN. We will now proceed. Thank you, Senator Bradley.

Dr. Peter Fox, Director of the Office of Policy Analysis from the Health Care Financing Administration. Your appearance, your testimony, your statement, your thought is essential, and we are gratified you could come to us today from your position with the Department of Health and Human Services.

STATEMENT OF PETER FOX, DIRECTOR, OFFICE OF POLICY ANALYSIS, HEALTH CARE FINANCING ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. Fox. I do not have formal testimony. I would, however, like to make some remarks addressed principally to three areas. First, are some of the broader trends and issues in long-term care. Second, I would like to give a brief description of the major Federal programs that fund home health services. And, third, review some of the problems with these problems.

I believe it is important to face the issues of home health in the context of some of the overall trends and issues regarding the need for long-term care services. Long-term care is important across the whole age spectrum, from age zero to the day when people die, but it is particularly germane for the elderly.

Paramount among the pressures we as a society face is the aging of the population and the concomitant increase in disability with age. To illustrate the increase in disability, I might mention that roughly 3½ percent of the population aged 65 through 74 is unable to perform one or more activities of daily living, such as, eating or dressing.

The CHAIRMAN. What is that percentage?

Dr. Fox. Three-and-a-half percent for the age 65 to 74.

Among the population aged 85-plus, the percentage rises tenfold to 35 percent. By the year 2030, the total U.S. population will increase 40 percent. However, the aged population will double and the proportion of aged over age 75 will increase from 38 to 45 percent.

Thus, the need for long-term care will clearly increase dramatically. These figures have been widely reported in the popular press. What is less well understood is that the need for many long-term care services increases with the age much faster than the level of disability.

This is best illustrated by examining nursing home use. Whereas less than one quarter of the severely disabled adults who are nonaged are in nursing homes, 61 percent of those over age 85 who are severely disabled are in nursing homes. The major reason for this trend is the lack of family support, particularly by a spouse, among the very old.

Unmarried, including widowed, aged persons, are nine times as likely to be institutionalized as married persons. A key implication with highly significant policy ramifications is that the need for long-term care, including home health services, is related as much to the availability of family support mechanisms as to medical condition.

Less than half of the severely disabled aged are in nursing homes.

We have projected the use of nursing homes if current age-specific use rates continue. We estimate that the number of nurs-

ing home residents will rise by 132 percent by the year 2030; in other words, more than a doubling.

The cost of this care will be borne by the working population, which will increase only 16 percent. Therein lies a major source of social tension for the next generation, particularly when the trends with increased expenditures in the medicare and social security cash program are taken into account.

Many argue that institutionalization can be reduced by substituting other services, such as home health and homemaker services, adult day care, congregate housing, nutritional programs and so forth.

Various studies have projected that between 10 and 20 percent of skilled nursing facility patients and 20 and 40 percent of intermediate care facility patients receive the wrong level of care.

However, I would suggest that these estimates can be very misleading. In some cases, the level of care is too low rather than too high, although that does not happen that frequently, to be sure.

More importantly, the studies extant look only at the patient and do not consider the absence or presence of family support. They also tend to ignore mental conditions as a basis for institutionalization.

Although the evidence is only suggested, I conclude that most of the patients now in nursing homes need significant levels of service and many need to be in a protective living environment, if not in nursing homes.

Some have suggested that expanded home health benefits could save money by substituting for nursing home and other institutional care. Whether or not this would occur depends on the specific design of the program in question.

I would submit, however, that available empirical studies at the very least bring into question the notion that budgetary savings can be achieved by expanding benefits under the current fee-for-service, open-ended payment mechanism such as that embodied in medicare and medicaid.

Although the cost per person served may be less, more beneficiaries would typically receive services and expenditures would increase as a result.

I want to emphasize that this is not to argue against expanded home health programs I simply want to suggest that the expansion may not be justified on the grounds of achieving savings.

I would now like to discuss the three major Federal programs that fund in-home services. The budgets for all three programs have increased significantly in recent years. However, the unmet needs are still considerable.

Medicare is intended predominantly for acute patients. It covers skilled nursing, physical, occupational and speech therapy, home health aid services, medical/social services, and medical supplies and equipment.

The eligibility requirements are most restricted. The beneficiary must be confined to his or her residence. The services must be prescribed by a physician and the beneficiary must need skilled nursing care, or physical, or speech therapy.

We have, however, seen a rapid increase in medicare expenditures for home health services. In 1969, medicare spent \$635 million for home health services, a fivefold increase in 5 years.

Under medicaid, home health benefits are a mandatory service in all State programs. The potential for coverage is still very broad. However, most States have elected a narrow program similar to that of medicare.

In 1978, \$211 million was spent under medicaid, an eightfold increase in 5 years. However, this accounts for just over 1 percent of all medicaid expenditures. Further, New York State alone accounted for 80 percent of all medicaid home health expenditures.

In addition to home health services, States have the option of providing personal care services. In the 12 States using this option, individuals not employed by home health agencies provide home-making and attendant care services.

Title XX services are optional with the State. Each State has its own allocation and may or may not elect to use some of the money for in-home services. They may cover chore, homemaker and home health aid services.

In fiscal year 1977, \$366 million were spent for in-home services under title XX.

Let me now mention some of the major problems with Federal programs. First is in the inadequate coverage of many services, particularly social services outside of the nursing home. Second is the artificial split between medical and social services implied in our programs.

This creates problems of coordination and beneficiary confusion.

Third, there is wide variation in the availability and use of services across geographic areas. Even under the medicare program, a program with a nationally determined benefit package, there is more than an eightfold variation by State per beneficiary.

A fourth problem is fraud and abuse, which has been documented in several reports of the General Accounting Office. Some of the abuses include billing for services not rendered, payroll padding, improper allocation of cost, and excessive overhead.

I would hasten to add that our regional office people tell me that this kind of fraud and abuse is not a significant problem in the State of New Jersey. It is, however, a more severe problem both to the north and south of us.

Finally, there are incentives embodied in our programs to use institutional services where noninstitutional services might suffice. For example, in some States, including the State of New Jersey, there are higher income eligibility standards for patients in nursing homes than for patients who are not in nursing homes, and this under medicaid.

So, a beneficiary with a given level of income might be eligible for nursing home care but not home health services.

The relationship between medicaid programs and other programs; the various income support programs—housing, food stamps and so forth—is very complicated and, in some cases, includes biases against the use of the institution.

The interactions among these programs, I submit, are not terribly well understood in some instances.

In conclusion, long-term care, in my view, is perhaps the most important social issue of the next decade. It differs from acute medical care in at least two important respects: First is the mix of social and medical services that it embodies.

Since social services are now typically provided by the family, there is great danger of monetizing, through public programs, services that are now provided and that do not entail financial transactions.

A second important distinguishing characteristic is the almost total absence of third party coverage for long-term care services whether in a nursing home or outside of the nursing home.

This is an extremely complex area. I think that the kind of hearings that are being held this afternoon and the conference tomorrow are most important in beginning to frame the issues and to start to address solutions.

I would like to wish the participants in tomorrow's conference the best of success in grappling with the critical issues we face. Thank you very much.

The CHAIRMAN. Thank you very much, Dr. Fox.

I wonder if we could just develop here some of the more specific descriptions of the effectiveness of what is now in place in terms of providing for home health care. When you are talking about home health care, are you talking about the other range of personal and social needs, or are you strictly talking about the medical part of home health care?

Dr. Fox. I probably used that term more loosely than I should have. I really mean to include in-home services, which would encompass medical as well as social services.

The CHAIRMAN. Then, you are talking about those services that are needed to promote the opportunities for independence, at least independent living apart from an institution, is that right?

Dr. Fox. That is correct. There are other services that are terribly important and that I think are often neglected that also promote independence. These would include adult day care and perhaps more importantly, congregate living arrangements or various housing arrangements that could evolve which would be an alternative certainly to nursing home care.

The CHAIRMAN. What are the types of services that you consider most promising in promoting the possibility of independent living for older people?

Dr. Fox. There are a whole range of services. I am not sure I personally have the knowledge of the field to tell you which is more important, but you do have various housing arrangements such as congregate living, domiciliary care, care that might be provided in a day care center or some other central facility where the individual spends several hours a day but goes to their own residence in the evening, and then various forms of in-home services both medical and social, including nutritional services.

The other service is physical adaptations to the home that can be helpful to some elderly—

The CHAIRMAN. A lot of these are good ideas, solid ideas, but, with very limited empirical evidence to work with, we don't know just how much they could contribute. I fought to get our congregate housing bill enacted in 1976; fought with the Department of Hous-

ing and Urban Development to keep it in; and then struggled to get some money for it.

This year we got the \$10 million for it, but the original budget, when it was presented, had zero for it. That is our problem. There are a lot of sound ideas that just have not been implemented.

That is what I hope we might learn here today. What are those good delivery systems that, if we could bring them together, would offer greater promise than we have today?

There are all kinds of problems, aren't there, with the present two, really three, titles in the Social Security Act which relate to home health care services, plus the myriad of State, local government, and private activities?

Are you people in policy looking at bringing this together as our Senate bill does, S. 2809, in terms of greater rationalization of the delivery effort?

Dr. Fox. Yes, we are. We are looking at a series of alternatives. I don't think we have any magic answers. We are looking at alternatives that are really quite different from your bill and also looking at the kinds of solutions that are embodied in your bill.

The CHAIRMAN. There is another bill that Representatives Pepper and Waxman put in, H.R. 6194. Are these before you people in policy analysis?

Dr. Fox. Yes, they are. Let me make one distinction though. What we are trying to do right now is really to take a step further back from either of those bills and to ask some fairly fundamental questions like: Is building on a medicare/medicaid approach the right way to go? Is medicare/medicaid the best way for dealing with this particular problem? So that while we are looking at the specifics of both of those bills, and those are really the two major bills that we have considered, we are looking at other options as well.

Senator BRADLEY. You mentioned medicaid and medicare and the reimbursement policies toward nursing homes. Do you think there have been mistakes in our policies in these areas and, if so, what are the mistakes?

Dr. Fox. I am not sure I am prepared to give you a comprehensive answer to the question. The expenditures that we have seen under medicaid, as best I can tell, were simply not anticipated when medicaid was originally passed.

The nursing home expenditures have been the fastest rising component of health care expenditures in the last 5 years and we have seen in a 5-year period a 50-percent increase in the nursing home population served by medicaid.

That is not necessarily a bad thing. It is just what the statistics show.

Senator BRADLEY. You say that no one was able to predict that?

Dr. Fox. I am not aware of it having been predicted. The need for long-term care services generally is very difficult to define because it really does depend on the availability of outside support mechanisms.

Again, let me reiterate the statistic I gave earlier. I realize I threw out a lot of numbers in a short period of time. The probability of being in a nursing home is nine times greater for somebody who is unmarried as somebody who is married, which would indi-

cate that a need has to be defined not only in terms of the medical condition of the patient but also in terms of other sources of support.

And I don't think we know very well how to build into Federal programs the major determinants of need.

Senator BRADLEY. How did you arrive at that number, nine times more for unmarried persons? I know the commonsense rationale, but what went into your assessment of the probability?

Dr. FOX. That is based on actual surveys.

Senator BRADLEY. You mean, presently there are nine times more unmarried people in nursing homes than married people?

Dr. FOX. No. For a given number of people who are married and the same number of people who are unmarried, the chances of the unmarried person being in the nursing home are nine times greater as for the married person.

Senator BRADLEY. How did you get that?

Dr. FOX. It is based on surveys that actually go into nursing homes and ask patients whether they are married or not and then comparing those numbers against general population numbers. They are not guesses. They are based on actual surveys.

Senator BRADLEY. But they are based upon the present nursing home population?

Dr. FOX. That is correct.

Senator BRADLEY. What does that say about future nursing home populations: Are they are going to stay at the same ratio of married to unmarried though increasing in total numbers?

Dr. FOX. I don't think we really know and partly, that depends on Government decisions. For example—and some States are starting to do this now—if States simply put a limit on the number of nursing home beds then people who would otherwise be in nursing homes won't be in the nursing homes.

I am not suggesting that this a good thing. In fact, if other services aren't made available, it may be a very bad thing. But what that would do to those ratios, I am not sure I can predict.

Senator BRADLEY. So certainly, if you are looking for mistakes of medicaid reimbursement, one of them was that we underestimated the number of people who would actually be in nursing homes.

Are there any other mistakes that you think were made in the original concept of medicaid reimbursement policy?

Dr. FOX. I really think the basic question, and it is arguable either way, is whether the medicaid funding mechanism is the best funding mechanism for long-term care services.

Senator BRADLEY. Present the committee with a couple of alternatives.

Dr. FOX. One alternative that we are examining—I am not saying we are advocating it—is taking moneys that are now spent under medicaid, and possibly some other programs such as, Administration on Aging Programs, and redistributing the money in a grant program to State and local governments.

Senator BRADLEY. The block grant approach.

Dr. FOX. Yes and no. The term "block grant" usually means to some people putting the money out on the stump and closing your eyes as far as how it is spent. One could do that or one could build in a series of controls. That is a policy decision.

Senator BRADLEY. Is that what you are testing with the money that you are now spending, the so-called channeling agency demonstration program?

Dr. FOX. No, we are not, and it would be very difficult to test the block grant under our current authorities.

Senator BRADLEY. What are you testing in your channeling program?

Dr. FOX. First, we are testing whether a channeling mechanism, rather similar to the preadmission assessment mechanism in your bill, makes sense in terms of cost, in terms of where patients go, and in terms of patient outcome.

We are building upon that basic concept and in some of the sites are funding additional services, services that would not normally be paid under medicare and medicaid. We will be doing that in two ways. One is through a separate grant allocation and that is, in fact, what is being done in this State, and also through medicaid waivers which would create an open-ended entitlement program for different kinds of services that medicaid does not fund.

Senator BRADLEY. What are we going to learn from the demonstration program?

Dr. FOX. Hopefully, we will learn about the cost and effectiveness of the channeling agency approach and I really think that is an open issue.

Second, we will learn about what the availability and financing of alternate services does to the patient and to the use of nursing homes.

Senator BRADLEY. One of the things that attracts me to this area is the possibility of actually saving money by treating people in their homes instead of sending them to hospitals where, as you know, the reimbursement is sometimes \$200, \$300, and \$400 a day. You maintain that a home health care program will not lead to deinstitutionalizing people; is that correct?

Dr. FOX. What I said—and one has to be a little bit careful here—is that a home health benefit that is essentially an open-ended entitlement will result in some deinstitutionalization and for the patients currently in the nursing home now treated at home, the cost per patient served will be less, to be sure.

But I am also suggesting that a totally new population will be served. That may be a good thing. I am not saying it isn't. But the net effect is that public expenditures will rise as a consequence.

Senator BRADLEY. So what you are saying is that it will cost the public less to maintain a person with the same or similar services in their home than it costs now to keep that person in a nursing home, but that the population will expand.

Dr. FOX. That is correct.

Senator BRADLEY. How do you project that demand?

Dr. FOX. We don't know how to project it very well. In making the general assertion we looked to certain experiments that had been conducted. There was, for example, the best study I have seen that entailed randomizing patients between the current benefit package on one hand and various combinations of adult day care and home health services.

This was done, I believe, at six sites and it shows, I think fairly conclusively, an increase in total expenditures. Now, it is danger-

ous to draw conclusions off of a single study. We have looked at the other studies. They are less clean. None of them are totally clean.

They are less clean in terms of the research design. But, nonetheless, we have reached the same conclusion being that while the cost per person served may drop, the number of people served increases.

Again, to come back to a statistic I used earlier, less than half of the severely disabled aged are in nursing homes, so that there is a big population who, on medical grounds, could qualify for nursing home care.

Senator BRADLEY. In your test was this the population that expanded, the severely disabled aged? What was the population that expanded?

Dr. FOX. I believe it was but I would have to go back to the specific studies to know what the population was.

Senator BRADLEY. Could you do that and submit that for the record? If this study takes a crack at trying to assess demand, I think it will be an important contribution to our analysis of the problems we must resolve.

Dr. FOX. Yes, we can.

The CHAIRMAN. Could I just amplify that last inquiry? Where you have been demonstrating and studying will you be able to reflect the number of people who are not served that are in need of the services? Is there any way that you are now equipped to make judgments on that population, the underserved who need those services?

Dr. FOX. That is really very hard to do because to the extent that the services are now provided by family, where the person has family, it is very difficult to say whether they need services or not.

And I certainly don't want to infer that disabled people with family do not need services. In fact, the availability of home health services may make all the difference in the world to that person as to whether they end up in an institution.

The CHAIRMAN. You are confident in saying that there will be no cost saving because the numbers will increase of those who are receiving services, and, therefore, we will not get a reduction of total cost in terms of the institutionalization not being necessary?

Dr. FOX. I would argue that the evidence, while not totally conclusive, is very strongly suggestive. One can put artificial limits on one kind of care or another and achieve a savings in that manner, but what I believe the evidence shows is that—

Senator BRADLEY. This is the evidence from one study?

Dr. FOX. No, it comes from more than one study. As I say, there is one study that is a little bit cleaner than the others because it did entail randomization of patients.

Senator BRADLEY. What were the other studies?

Dr. FOX. We are getting now results out of a project in Georgia, the Triage project in Connecticut, and a project in Monroe County, N.Y.

The CHAIRMAN. We make empirical studies by going to places where there are concentrations of older people, particularly in some of our housing programs. We see it all the time—people that just need some modicum of support so they can stay in their apartment in a public housing area.

Without that modicum they have got to go to an institution. This isn't a scientific study, but we see it all the time.

Dr. Fox. Again, let me be clear. I am not questioning that there are people now in nursing homes who could be cared for without being in the nursing home, so I am in no way contradicting what you are saying.

Senator BRADLEY. Mr. Chairman, may I ask him just one more question?

The CHAIRMAN. Yes.

Senator BRADLEY. With this level of uncertainty surrounding cost, use, and so forth, do you think that the idea of a study after the 3-year demonstration program embodied in S. 2809 makes sense—having the General Accounting Office and the Congressional Budget Office take a look at these questions after they have been demonstrated in 10 States for a couple of years?

Dr. Fox. Without commenting on what the size of the demonstration ought to be, I know a very few areas where demonstrations can be more helpful than the long-term care area. So, the answer, generically, is yes, I think it is important.

Senator BRADLEY. Thank you.

The CHAIRMAN. Are you going to be staying around, Dr. Fox?

Dr. Fox. I will be here for the afternoon.

The CHAIRMAN. You are not staying over for tomorrow?

Dr. Fox. No, sir.

The CHAIRMAN. I would like, informally, to talk to you before the afternoon is over.

Dr. Fox. I would like that too.

The CHAIRMAN. We now invite our panel of service program directors.

Thank you for coming today. I understand you folks will be staying through the meetings tomorrow, too.

STATEMENTS OF ROSEMARY CUCCARO, EXECUTIVE DIRECTOR, VISITING NURSE AND HEALTH SERVICES, ELIZABETH, N.J.; GEORGE BATTEN, EXECUTIVE DIRECTOR, WEST ESSEX COMMUNITY HEALTH SERVICE; KENNETH WESSEL, EXECUTIVE DIRECTOR, VISITING HOMEMAKER SERVICE OF PASSAIC COUNTY, A PANEL

Mrs. CUCCARO. My name is Rosemary Cuccaro. I am an executive director of the Visiting Nurse and Health Services, Elizabeth, N.J. We cover 15 towns in Union County, a population of 420,000, and probably one of the highest concentrations of senior citizens.

I would like to preface my statement, first of all, by saying that we in New Jersey are very fortunate in that our State medicaid unit has been very sensitive to the needs of long-term care for senior citizens and we have a very happy relationship with them.

The problem with medicaid is the income eligibility. They are allowed \$210 a month to be eligible for home care and about \$530 a month to be eligible for nursing home placement.

I would like to set a little scenario. About 3 years ago in our agency we became very strapped for space. Consequently, the phone ended up outside my office and for the next 6 months I heard many, many things that indicated to me changes had to be made in the system.

I will give you a little example. An 83-year old woman called. She is very ill. She is having trouble breathing. Her legs are swollen. She doesn't know where the person that took care of her is coming from.

"What is your name, ma'am? Where do you live?" We checked with our nurse secretaries. Nobody knows this woman. All right, "Give us your phone number. And do you mind if we send a nurse out to visit you?" We get the patient's phone number, ask her her doctor's name, put one intake nurse on the phone to call all the other agencies in the county to see if they know this person and who is taking care of her.

We then put the other intake nurse on the phone to call the physician to find out the patient's diagnosis and ask permission to visit.

By this time an hour has gone by. We put the supervisor on the phone to find a nurse to make the visit. By this time an hour has gone by and four people have worked on this case. It indicated very strongly that something had to be done with the system.

So, the Visiting Nurse and Health Services in cooperation with the Union County Division on Aging began to develop a mini-title XXI in Union County as proposed in your bill, S. 2809. The purpose was, No. 1, to maximize the funds, to provide the most services to the most people and prevention and/or delay of institutionalization, both acute and long-term care.

The problem, as we defined it, was threefold: First, the system needed revision to facilitate service delivery. There are many elderly and disabled with varying types of needs. This particular population is growing. Most of this population could be cared for at home with the proper support systems.

Second, was the nursing home industry. Prior to 30 years ago, people were cared for at home. But, with governmental funding for nursing homes, they proliferated without proper policing.

Medicare perpetuated this and medicaid followed suit. Now, evaluation of the nursing home industry shows the tremendous amount of Federal and State—and we are talking about taxpayers' money—funding paying for services in this industry.

If we are to pull back on this funding, community services must be further developed utilizing all available resources, including family.

The third problem was financial resources. There is not enough money to satisfy the wants of everybody. Funding is fragmented and uncoordinated. Some people get duplicate services and others none.

We are developing system abusers, if I can give you an example of this. We have one of our aides going into a home 3 days a week to provide personal care, do light housekeeping and shopping.

She cancels the visit one day because we were short staffed and told the patient she would visit the next day. The next day she makes a visit to that home and finds an aide in from another service agency.

Therefore, the patient was getting 5-day-a-week service when the need indicated she did not need it. Two agencies were involved and somebody else was going without service.

The division on aging in Union County was very sensitive to this problem because, needless to say, they get most of the calls in relation to senior citizens. So we sat down and talked and decided that, No. 1, they had to provide some funds to pick up for payment for care of the senior citizens once medicare cut off, because as each year goes by, the payment for services gets less and less.

So, our objective with the division on aging became to provide a coordinated system of comprehensive home care for Union County. The traditional home health services, such as nursing, physical therapy, speech therapy, homemaker, home health aids, nutrition, social work, et cetera, must be redefined to include all those services available in a hospital, but only to the extent needed.

The patient and family become part of the team and are helped to assume some responsibility. Our methodology was to, first, control intake—one phone number for people to call. Second, assign assessment teams—home health agency personnel, which are those who have been doing this for the past 80 years—the nurses. This is the district nurse of yesterday. She is the primary care nurse of today.

The physician was the patient's own. The plan of care was determined by the nurse, patient, family, and physician. Management of the case was by the nurse as was the provision of needed services. Reevaluation and adjustment of the plan of care was done on an ongoing basis.

Then we have to do case finding. We are monitoring the waiting list for nursing home placement. We are offering home care services if this patient is not known to us. This has been a very interesting experiment in our county.

The division on aging, again, has funded this position. We are gathering together all the nursing home waiting lists. We are finding the lists are duplicated; 75 percent of the patients who are at home are on home care through the support of the division on aging.

We are finding patients don't know that they are on the waiting list. Families have placed them on. They are being maintained at home and had no intentions of going to a nursing home.

We are finding that hospitals, because of their concern for the shortage of nursing home beds, are placing people on the waiting lists as soon as they go in the hospital, because they realize they may be on the list for 10 years.

Where is the funding coming from to do all this? It comes from medicare, medicaid, patient pay, title III of the Older Americans Act, United Ways, title XX of the Social Security Act, municipal funds, and others. These are all the sources of payment we are using in Union County.

Why is it important for all these funds to come through a single point entry? A patient may be title III today because he is considered long-term maintenance care. Medicare will not pay.

Now, like the 83-year-old woman that called us in the beginning, who is sick today, she may be getting services under title XX funds. My nurse goes in and finds this patient in the first stages of cardiac failure. Does the patient have to go to the hospital? Most likely not. What happened?

The patient felt well, so she stopped taking her medication. We contact the physician; patient resumes medication; we increase our services for 1 week to 10 days; put our aide in there; and the patient is put back on medicare B. We have now loosened up some title XX funds to be used for another patient for an interim period.

The home health agency is the only agency that has the ability, at this stage of the game, to manipulate funding sources from one to the other and maximize the use of the funds.

We are doing the coordination for other services: Meals on Wheels; transportation; chore services; congregate meals. We only have so much money to spend on Meals on Wheels. A typical example: We evaluate all requests for Meals on Wheels for various reasons. If a patient needs Meals on Wheels, what is the matter with her? Are other services needed? Are we going to serve a patient a meal when she may need medical care more than she needs the meal? Does the patient really need Meals on Wheels or could she go to a congregate meal site?

Here again, we just have so much money to spend on Meals on Wheels, and we must see that the money is used appropriately. Maybe we could arrange transportation services for this patient to a congregate meal site where she will not only get her meals, but also she will get the socialization and the availability of a health program which we have set up at most of our congregate feeding sites to take care of the so-called well senior citizen.

This is the type of system we are working to pull together in Union County, but central intake is an all-important factor. Our recommendations would be: No. 1, we need consistency. Services should be provided through the home health agency, which is already the certified agency designated to provide services under titles XVIII and XIX of the Social Security Act.

In Union County, title III funds, municipal funds, and United Way funds are already coordinated into this system.

There is no distinction under titles XVIII and XIX between a homemaker and a home health aide. The task does not determine the qualification of the person providing the service. The home health aide is part of the health team working for the same goals as the rest of the team.

No. 2, we need continuity of care: People need continuity of care providers and of services when they are sick and disabled. And this I must speak to. If you do not have central intake and you have a dozen agencies out there providing services, the elderly patient gets bounced back and forth like a volleyball.

She has an aide from our agency today; tomorrow she is no longer eligible for medicare, so she gets an aide from another agency. Two days later the other agency calls and says the patient is very sick, and she is bounced back to our agency again.

Elderly people are so confused about who is doing what, and when we talk in terms of five, six, seven agencies being involved in care, these poor people are really being thrown to the wolves, so to speak.

They need that significant, single agency to relate to. They need the ability to pick up the phone and be able to talk to that significant one who then will help to resolve some of her problems.

A change in job functions from day to day should not necessitate a change in personnel. A public health nurse is a generalist and must be prepared to meet all of the health and social problems that occur either directly or through the referral process.

The homemaker/home health aide remains the same person regardless of the chore needed on that particular day—personal care and/or housekeeping.

No. 3, we need coordination: There is a need to coordinate all the services offered in the community and to monitor the delivery of these services. Lots of times we refer but nobody ever follows up to see that the service was actually provided.

We are aware of all the other alternatives to home care, such as, health day care, respite care, and all the other things that Dr. Fox talked about before. We are aware that people are placed in nursing homes inappropriately.

We are talking about home care as only being one part of the total system. Until the funding for the system is sufficient, we are going to flounder the way we have been floundering.

I have been, for 8 years, a director of the Visiting Nurse and Health Services, and every year we go out and we beg, and I literally mean beg, for funds to continue to provide the services that we are required, as a community agency, to provide to all of our senior citizens and to all of our citizens.

I have one other comment. The reality of Federal funds demanding a voluntary nonprofit agency to supply a 25-percent share of the funding is a deterrent to many agencies using title XX and title III funds.

Most of us are using our United Way Funds to provide our 25-percent share of the funds. And what has happened is we are using the United Way Funds on a very restrictive basis. All of our funds are going to the elderly, or to child abusers. It does not leave us any money to take care of that famous neglected group, 45 to 65 years of age.

I thank you.

[The prepared statement of Mrs. Cuccaro follows:]

VISITING NURSE AND HEALTH SERVICES
PUBLIC HEARING ON TITLE XXI AND LONG TERM CARE

PURPOSE

The Visiting Nurse and Health Services, in cooperation with the Union County Division on Aging has developed a Mini-Title XXI in Union County. The purpose: 1. to maximize funds to provide the most services to the most people. 2. prevention and/or delay of institutionalization, both acute and long term.

I. PROBLEM

- A. System needs revision to facilitate service delivery. There are many elderly and disabled with varying types of needs. This particular population is growing. Most of this population could be cared for at home with the proper support systems.
- B. Growth of nursing home industry (proprietary-warehouses). Prior to 30 years ago, people were cared for at home. But with governmental funding for nursing homes, they proliferated without proper policing. Medicare perpetuated this and Medicaid followed suit. Now, evaluation of the nursing home industry shows the tremendous amount of federal and state (taxpayers money) funding paying for services in this industry. If we are to pull back on this funding, community services must be further developed; utilizing all available resources, including the family.
- C. Financial Resources
- There is not enough money to satisfy the wants of everyone. Funding is fragmented, uncoordinated. Some people get duplicate services and others none (i.e., homemaking and meals on wheels). We are developing system abusers.

II. OBJECTIVE

Provide a coordinated system of comprehensive home care for Union County. The traditional home health services such as Nursing, Physical Therapy, Speech Therapy, Homemaker/Home Health Aides, Nutrition, Social Work, etc. must be redefined to include all those services available in a hospital but only to the extent needed. The patient and family become part of the team and are helped to assume some responsibility.

III. METHODOLOGY

- A. Control intake; one phone number for people to call.
- B. Assessment teams; home health agency personnel (those with the experience of doing this for the past 80 years).
 - 1. Nurse - district nurse of yesterday, primary care nurse of today.
 - 2. Physician - patient's own.
 - 3. Plan of care determined by the nurse, patient and family and physician.
 - 4. Management of case by the nurse and provision of needed services.
 - 5. Re-evaluation and adjustment of plan of care on an ongoing basis.
- C. Case Finding
 - Monitor waiting list for nursing home placement and offer home care services as needed.

D. Funding to do the above from various sources.

- | | | |
|-------------|-----------------|--------------------|
| 1. Medicare | 3. Patient Pay | 5. Title XX |
| 2. Medicaid | 4. Title III | 6. Municipal funds |
| | 7. United funds | 8. Others |

E. Coordination of other services

- | | |
|--------------------|---------------------|
| 1. Meals on Wheels | 3. Chore services |
| 2. Transportation | 4. Congregate meals |

This is the system we are working to pull together in Union County.

Central intake is an all important factor.

RECOMMENDATIONS

1. Consistency

- a. Services provided through the home health agency who are already the certified agency designated to provide services under Titles XVIII and XIX. In Union County, Title III, municipal funds and United Way funds are already coordinated into this system.
- b. There is no distinction under Titles XVIII and XIX between a homemaker and a home health aide. The task does not determine the qualification of the person providing the service. The home health aide is a part of the health team - working towards the same goals as the rest of the team.

2. Continuity of Care

- a. People need continuity of care providers and services when they are sick and disabled.

Continuity of Care (Cont'd)

- b. Change in job functions from day to day should not necessitate a change in personnel. A public health nurse is a generalist and must be prepared to meet all of the health and social problems that occur either directly or through the referral process.
 - c. The Homemaker/Home Health Aide remains the same person regardless of the chore needed on that particular day; personal care and/or housekeeping.
3. Coordination
- a. There is a need to coordinate all the services offered in the community and monitor delivery of these services.

The CHAIRMAN. Thank you very much, Mrs. Cuccaro.

Have you reviewed the two major bills that we mentioned, our Senate bill, S. 2809, and the House bill, H.R. 6194?

Mrs. CUCCARO. I have read the channeling grants. I have read Mr. Waxman's bill, H.R. 6194. I think the one thing I would like to comment on is the setting up of another administrative body in a community to do assessment only, and then referring clients to another agency.

The home health agency has been doing assessment. It is their area of expertise. The problem I see with setting up another administrative agency is a criteria for benefits. If we set up another administrative agency, say, in Union County and, of course, I can only speak from the framework of my own county, but I am sure everybody experiences the same problem—if we set up another assessment team out there to do all the administrative work and the assessments, they are going to call me and tell me a patient is eligible for medicare, and would I please supply all the services she needs.

My agency will go out and make a home visit. We have the law books in our agency. We are the ones they check for fraud and abuse. We are going to go out and say that patient is not eligible for medicare A or B at this stage of the game.

The patient has already been seen by two agencies and gotten nothing yet, and, I dare say, probably 10 days have gone by.

Senator BRADLEY. Could I just follow up?

The CHAIRMAN. Sure.

Senator BRADLEY. Would consolidating all of this into a title XXI help your situation as we propose in our bill, S. 2809? Would the State designate which would be the responsible party in each county? You might be the responsible party for the whole thing.

Mrs. CUCCARO. Right.

Senator BRADLEY. Does that make sense to you?

Mrs. CUCCARO. Yes. I realize that we are in a different environment and who the responsible party would be would depend on what county or even what State you are in. But I think you need to look at the system, that already has started to develop and maybe it is workable for other agencies.

Senator BRADLEY. So that title XXI would help you by consolidating the programs and making one agency responsible in a certain geographic area.

Mrs. CUCCARO. Yes, sir.

The CHAIRMAN. Now, Mr. Batten.

Mr. BATTEN. Thank you. My name is George Batten and I am legislative chairman of the Home Health Assembly of New Jersey and executive director of the Community Health Services located in Essex County.

West Essex Community Health Services is a private nonprofit agency with a community board of directors. We are licensed by the State of New Jersey as a home health agency and have contracts with medicare, medicaid, and New Jersey Blue Cross to provide home health services.

I want to talk to you about community based agencies and our financing problems. Community agencies, to a large extent, reflect the flow of money from various funding sources. Each Federal program has its own procedures and policies to administer their program.

This is true of title XVIII, title XIX, title XX, and title III of the Older Americans Act, a Federal initiative not mentioned in the proposed Title XXI. Title XXI should coordinate with titles XVIII, XIX and XX as well as title III of the Older Americans Act.

Our agency can be characterized as a hospital without walls. We would like to be paid in a similar manner as hospitals. An example of such reimbursement fragmentation is meals. Meals are covered in hospitals and nursing homes, but for those needing such a basic necessity at home, a local initiative is required for Meals on Wheels.

Some Meals on Wheels programs are funded under title III. This should be an eligible service under the proposed title XXI Home Health Services, the same as physical therapy, speech therapy, occupational therapy, medical social worker and nursing services. What is worse, in your proposed legislation, it will cover meals in adult day care, but not at home.

The goal of this Federal initiative to meet the stated purposes should be legislation to foster strong, effective, efficient community agencies to serve patients and families out of institutions. The more complicated you make it for community agencies, the less strength they will have to provide these necessary services.

Now, I will discuss several of the problems which the proposed legislation in title XXI continues to foster, not solve. The legislation, S. 2809, apparently will provide for continued Federal financial support and therefore existence of titles XVIII, XIX and XX home health agencies, along with a new title XXI home health agency.

Thus, this situation will further fragment these existing community-based agencies. I recommend that all home health services

now funded under titles XVIII, XIX, XX and title III of the Older Americans Act be lumped under the new title XXI.

This would necessitate a renaming of this legislation to reflect acute level services now provided by home health agencies, such as my own, under titles XVIII and XIX. To allow title XVIII and a new title XXI home health agency to operate separately in the same community would further confuse the present situation.

My agency would have to decide if we wanted to be a title XXI agency while continuing to be a title XVIII and title XIX agency, knowing that the reimbursement formulas, procedures and policies would be different although the patient would receive similar services probably from the same nurse, home health aide, and so on.

Our second problem. Home health services as described in S. 2809 are substantially changed from the home health services as described, and commonly known, in titles XVIII and XIX. That difference is home health aide/homemaker services, which are separately listed in S. 2809.

Such homemaker/home health aide services are directly or indirectly provided by New Jersey home health agencies on a daily basis as an integral part of our home health services. Thus, homemaker/home health aide services should be listed under the heading "Home Health Services" in the bill.

In addition, the respite care services should also be listed under the Home Health Services section. This type of respite by live-in aides is clearly an extension of our present home health aide service when a spouse or daughter is working during the day. Live-in aides expand the aide services to 24 hours a day and allow the daughter or primary caretaker to take a vacation or needed rest.

The third problem. Several items of reimbursement which should be mentioned have not been mentioned at all in the legislation. I have already discussed the subject of meals, which, it is proposed, are only to be paid for in adult day care. It should be included under home health services.

Another is diet counseling in the home. A third is transportation, provided by an agency bus or vehicle, not to the home, but for patient movement to doctors' offices or whenever appointments may be necessary for the care of their condition.

My point is, home health is too narrowly defined in the legislation and other Federal legislation now in existence is paying for chore services and other activities which rightly should be included in a comprehensive home health care services. The opportunity to consolidate under the proposed title XXI is here, but it must be recognized.

The fourth item to be addressed is the proposed fee-for-service reimbursement. The legislation proposes a cap on average wages, visits per day, and transportation, which appears to me a bureaucratic mess.

I would have to review any existing similar systems before supporting such a proposal. If such a drastic change is to be made, it should be changed from a fee-for-service system which only provides the incentive to offer more visits.

A lump-sum method such as a monthly figure would be a more reasonable system. My experience with the Federal medicare caps on physical therapy reimbursement is indicative of what occurs:

All physical therapists that work for me want the cap figure, and administrators such as myself have a very difficult time paying lower than the cap, even if a particular physical therapist should be reimbursed less than the cap.

Further, I question the 20 percent cap on administrative costs. I question what the basis is. I could easily meet this percentage if medicare rules and regulations on surveys, reporting, and paperwork were relaxed. I don't see that happening under title XXI.

Continued will be the intermediary that is specified in the legislation reviewing our invoices and assorted photocopying requirements. Newly added will be the process of setting charges, including a 30-day comment from local governments and a completely new level of community review proposed by the preadmission screening service with the associated paperwork, reporting, et cetera.

The 20 percent is arbitrary and not realistic. Further, no mention in the legislation is made for development money which is necessary for startup and expansion. On the good side, I find the proposal of copayments with income adjustments conducted by the Secretary of Health and Human Services worth considering.

I will say, from a provider's point of view, the proposed copayments would be impossible to administer if this was the responsibility of the provider. I question though how this provision will work and will the cost of such a Federal bureaucracy to administer it truly save the 10 percent or less in program costs?

Problems today, which Mrs. Cuccaro has already touched upon, include the separate approval and reimbursement system for title XVIII and XIX. Fortunately for us in New Jersey, the audit for these two programs is conducted by the same intermediary who utilizes the same reimbursement principles.

However, under title XX in New Jersey there is a mixture of line item reimbursements and purchase-of-service, or fee-for-service reimbursement arrangements. Unfortunately, the line item reimbursement has not covered appropriate overhead and other items, such as transportation and occupancy costs. This is confusing because one Federal health program will cover such items and others will not.

Title III of the Older Americans Act is also administered similarly to title XX. Audits for title III and title XX are different from those audits for titles XVIII and XIX, creating double and triple work of recording. Further, quarterly field audits are conducted for some title XX programs while leaving the others to yearly audits.

I have tried to state several of the problems reflected in the fragmental flow of Federal home health money. Title XXI can solve many of these problems.

I thank you for the opportunity to present my comments.

[The prepared statement of Mr. Batten follows:]

west essex community health services, inc.

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FINANCING HOME HEALTH SERVICES

HEARINGS, PRINCETON, N.J.

NOVEMBER 23, 1980

GOOD AFTERNOON, MY NAME IS GEORGE BATTEN, I AM LEGISLATIVE CHAIRMAN FOR THE HOME HEALTH AGENCY ASSEMBLY OF N.J. AND THE EXECUTIVE DIRECTOR OF THE WEST ESSEX COMMUNITY HEALTH SERVICES. WEST ESSEX IS A PRIVATE NON-PROFIT AGENCY WITH A COMMUNITY BOARD OF DIRECTORS. WE ARE LICENSED BY THE STATE OF NEW JERSEY AS A HOME HEALTH AGENCY AND HAVE CONTRACTS WITH MEDICARE, MEDICAID AND N.J. BLUE CROSS TO PROVIDE HOME HEALTH SERVICES.

I WANT TO TALK TO YOU ABOUT COMMUNITY BASED AGENCIES AND OUR FINANCING PROBLEMS. COMMUNITY AGENCIES, TO A LARGE DEGREE, REFLECT THE FLOW OF MONEY FROM VARIOUS FUNDING SOURCES. SINCE A LARGE PORTION OF THIS FUNDING COMES FROM FEDERAL SOURCES, THESE AGENCIES REFLECT THE FEDERAL FRAGMENTATION. AS THE FEDERAL SOURCES ARE FRAGMENTED, THERE ARE MANY FUNDING SOURCES FOR COMMUNITY BASED HOME HEALTH SERVICES, AND THE AGENCIES GROW UP AND EXIST FRAGMENTED, EACH SERVING CERTAIN PORTIONS OF THE PATIENT'S OR CLIENT'S NEEDS. PATIENTS, TO MEET THEIR PARTICULAR NEEDS, MUST SUFFER THE INCONVENIENCE OF SOLICITING SEVERAL COMMUNITY



BASED AGENCIES.

EACH FEDERAL PROGRAM HAS ITS OWN PROCEDURES AND POLICIES TO ADMINISTER THEIR PROGRAM. THIS IS TRUE OF TITLES 18, 19, & 20 AND TITLE III OF THE OLDER AMERICAN ACT, A FEDERAL INITIATIVE NOT MENTIONED IN THE PROPOSED TITLE 21. TITLE 21 SHOULD COORDINATE WITH TITLES 18, 19, AND 20 AS WELL AS WITH TITLE III OF THE OLDER AMERICAN ACT.

OUR AGENCY CAN BE CHARACTERIZED AS A "HOSPITAL WITHOUT WALLS." WE WOULD LIKE TO BE PAID IN A SIMILAR MANNER AS HOSPITALS. AN EXAMPLE OF SUCH REIMBURSEMENT FRAGMENTATION IS MEALS. MEALS ARE COVERED IN HOSPITALS AND NURSING HOMES, BUT FOR THOSE NEEDING SUCH A BASIC NECESSITY AT HOME, A LOCAL INITIATIVE IS REQUIRED FOR "MEALS ON WHEELS". SOME "MEALS ON WHEELS" ARE FUNDED UNDER TITLE III. THIS SHOULD BE AN ELIGIBLE SERVICE UNDER TITLE 21 HOME HEALTH SERVICES, THE SAME AS PHYSICAL THERAPY, SPEECH THERAPY, OCCUPATIONAL THERAPY AND MEDICAL SOCIAL WORK. WHAT'S WORSE IS THAT THIS PROPOSED LEGISLATION WILL COVER MEALS IN "ADULT DAY CARE" BUT NOT AT HOME.

THE GOAL OF THIS FEDERAL INITIATIVE TO MEET THE STATED PURPOSES SHOULD BE LEGISLATION TO FOSTER STRONG, EFFECTIVE AND EFFICIENT COMMUNITY AGENCIES TO SERVE PATIENTS AND FAMILIES OUT OF INSTITUTIONS. THE MORE COMPLICATED YOU MAKE IT FOR COMMUNITY AGENCIES, THE LESS STRENGTH THEY WILL HAVE TO PROVIDE THESE NECESSARY SERVICES. I WILL NOW DISCUSS SEVERAL PROBLEMS WHICH S:2809 CONTINUES TO FOSTER, NOT SOLVE.

ONE, S:2809 APPARENTLY WILL PROVIDE FOR THE CONTINUED FEDERAL FINANCIAL SUPPORT AND THEREFORE EXISTANCE OF TITLES 18, 19, & 20 HOME HEALTH AGENCIES, ALONG WITH A NEW TITLE 21 HOME HEALTH AGENCY. THUS, THIS SITUATION WILL FURTHER FRAGMENT THOSE EXISTING COMMUNITY-BASED SERVICES. I RECOMMEND THAT ALL HOME HEALTH SERVICES NOW FUNDED UNDER 18, 19, 20 AND TITLE III BE LUMPED UNDER THIS NEW TITLE 21. THIS WOULD NECESSITATE A RENAMING OF THIS LEGISLATION TO REFLECT "ACUTE" LEVEL SERVICES NOW PROVIDED BY HOME HEALTH AGENCIES UNDER TITLES 18 & 19. TO ALLOW TITLE 18 AND NEW TITLE 21 HOME HEALTH AGENCIES TO OPERATE SEPARATELY IN THE SAME COMMUNITY WOULD FURTHER CONFUSE THE PRESENT SITUATION. MY AGENCY WOULD HAVE TO DECIDE IF WE WANTED TO BE A TITLE 21 AGENCY, WHILE CONTINUING TO BE A TITLE 18 AND TITLE 19 AGENCY, KNOWING THAT THE REIMBURSEMENT FORMULAS, PROCEDURES AND POLICIES WOULD BE DIFFERENT ALTHOUGH THE PATIENT WOULD RECEIVE SIMILAR SERVICES PROBABLY FROM THE SAME NURSE, AIDE, ETC.

TWO, HOME HEALTH SERVICES AS DESCRIBED IN S:2809 ARE SUBSTANTIALLY CHANGED FROM HOME HEALTH SERVICES AS DESCRIBED IN TITLES 18 AND 19. THAT DIFFERENCE IS HOME HEALTH AIDE/HOMEMAKER SERVICES WHICH ARE SEPARATELY LISTED IN S:2809. SUCH HOMEMAKER/HOME HEALTH SERVICES ARE DIRECTLY OR INDIRECTLY PROVIDED BY N.J. HOME HEALTH AGENCIES ON A DAILY BASIS AS AN INTEGRAL PART OF HOME HEALTH SERVICES. THUS, "HOMEMAKER-HOME HEALTH SERVICES" SHOULD BE LISTED UNDER THE HEADING "HOME HEALTH SERVICES". IN ADDITION "RESPITE CARE SERVICES" SHOULD ALSO BE LISTED UNDER THE HEADING "HOME HEALTH SERVICES". THIS TYPE OF RESPITE CARE

BY LIVE-IN AIDES IS CLEARLY AN EXTENSION OF OUR PRESENT HOME HEALTH AIDE SERVICE WHEN A SPOUSE OR DAUGHTER IS WORKING DURING THE DAY. LIVE-IN AIDES EXPAND THE AIDE SERVICES TO 24 HOURS PER DAY, AND ALLOW THE DAUGHTER OR PRIMARY CARETAKER TO TAKE A VACATION OR NEEDED REST.

THREE, SEVERAL ITEMS OF REIMBURSEMENT, WHICH SHOULD BE MENTIONED, HAVE NOT BEEN MENTIONED AT ALL. I HAVE ALREADY DISCUSSED THE SUBJECT OF MEALS, WHICH, IT IS PROPOSED, ARE ONLY TO BE PAID FOR IN "ADULT DAY CARE." IT SHOULD BE INCLUDED UNDER HOME HEALTH SERVICES. ANOTHER IS DIET COUNSELING IN THE HOME. A THIRD IS TRANSPORTATION, PROVIDED BY AN AGENCY BUS OR VEHICLE, NOT TO THE HOME BUT FOR PATIENT MOVEMENT TO A DOCTOR'S OFFICE OR WHATEVER APPOINTMENTS MAY BE NECESSARY FOR THE CARE OF THEIR CONDITION.

MY POINT IS, HOME HEALTH IS TOO NARROWLY DEFINED, AND OTHER FEDERAL LEGISLATION NOW IN EXISTENCE IS PAYING FOR CHORE SERVICES AND OTHER ACTIVITIES WHICH RIGHTLY SHOULD BE INCLUDED IN A COMPREHENSIVE HOME CARE SERVICE. THE OPPORTUNITY TO CONSOLIDATE UNDER TITLE 21 IS HERE, BUT IT MUST BE RECOGNIZED.

THE FOURTH ITEM TO BE ADDRESSED IS THE PROPOSED FEE-FOR-SERVICE REIMBURSEMENT; A CAP OF AVERAGE WAGES, VISITS PER DAY AND TRANSPORTATION APPEARS LIKE A BUREAUCRATIC MESS. I WOULD HAVE TO REVIEW ANY EXISTING SIMILAR SYSTEMS BEFORE SUPPORTING SUCH A PROPOSAL. IF SUCH A DRASTIC CHANGE IN PAYMENT IS TO BE MADE, IT SHOULD BE CHANGED FROM A FEE-FOR-SERVICE SYSTEM WHICH ONLY PROVIDES THE INCENTIVE TO OFFER MORE VISITS.

A LUMP-SUM METHOD SUCH AS A MONTHLY FIGURE WOULD BE A MORE REASONABLE REIMBURSEMENT SYSTEM. MY EXPERIENCE WITH FEDERAL MEDICARE CAPS ON PHYSICAL THERAPY REIMBURSEMENT IS INDICATIVE OF WHAT OCCURS: ALL PHYSICAL THERAPISTS WANT THE CAP FIGURE AND ADMINISTRATOR/MANAGERS HAVE A DIFFICULT TIME PAYING LOWER THAN THE CAP, EVEN IF A PARTICULAR PHYSICAL THERAPIST SHOULD BE REIMBURSED LESS THAN THE CAP.

FURTHER, I QUESTION THE 20% CAP ON ADMINISTRATION COSTS. WHAT IS THE BASIS? I COULD EASILY MEET THIS PERCENTAGE IF MEDICARE RULES AND REGULATIONS ON SURVEYS, REPORTING, AND PAPERWORK WERE RELAXED. I DON'T SEE THAT HAPPENING UNDER TITLE 21. CONTINUED WILL BE THIRD PARTY INTERMEDIARIES REVIEWING INVOICES AND THEIR ASSORTED PHOTOCOPYING REQUIREMENTS. NEWLY ADDED WILL BE THE PROCESS OF SETTING CHARGES INCLUDING 30 DAY COMMENT FROM LOCAL GOVERNMENTS AND A COMPLETELY NEW LEVEL OF COMMUNITY REVIEW BY A P.A.T. SERVICE, WITH ASSOCIATED REPORTING, PATERWORK, ETC. THE 20% IS ARBITRARY AND NOT REALISTIC. NO MENTION IN THE LEGISLATION IS MADE FOR DEVELOPMENT MONEY WHICH IS NECESSARY FOR START-UP AND EXPANSION. ON THE GOOD SIDE, I FIND THE PROPOSAL OF CO-PAYMENTS WITH INCOME ADJUSTMENTS CONDUCTED BY THE SECRETARY OF HEALTH AND HUMAN SERVICES WORTH CONSIDERING. I WILL SAY FROM A PROVIDER'S POINT OF VIEW, THE PROPOSED CO-PAYMENTS WOULD BE IMPOSSIBLE TO ADMINISTER IF THIS WAS THE RESPONSIBILITY OF THE PROVIDER. I QUESTION HOW THIS PROVISION WILL WORK AND WILL THE COST OF SUCH A FEDERAL BUREAUCRACY TRULY SAVE THE 10% OR LESS IN PROGRAM COSTS?

PROBLEMS TODAY FOR N.J. HOME HEALTH AGENCIES INCLUDE THE SEPARATE APPROVAL AND REIMBURSEMENT SYSTEM FOR TITLE 18 AND TITLE 19. FORTUNATELY, THE AUDIT FOR THESE TWO PROGRAMS IS CONDUCTED BY THE SAME INTERMEDIARY WHO UTILIZES THE SAME REIMBURSEMENT PRINCIPLES. HOWEVER, UNDER TITLE 20 IN NEW JERSEY THERE IS A MIXTURE OF LINE-ITEM REIMBURSEMENT AND PURCHASE-OF-SERVICE (FEE FOR SERVICE) ARRANGEMENTS. UNFORTUNATELY THE LINE-ITEMS HAVE NOT COVERED APPROPRIATE OVERHEAD AND OTHER ITEMS SUCH AS TRANSPORTATION AND OCCUPANCY. THIS IS CONFUSING BECAUSE ONE FEDERAL HOME HEALTH PROGRAM WILL COVER SUCH ITEMS, WHILE OTHERS WILL NOT.

TITLE III OF THE OLDER AMERICAN ACT ALSO IS ADMINISTERED SIMILARLY TO TITLE 20. AUDITS FOR TITLE III AND TITLE 20 ARE DIFFERENT FROM THE AUDITS FOR TITLE 18 AND TITLE 19, CREATING DOUBLE AND TRIPLE WORK OF RECORDING. FURTHER, QUARTERLY FIELD AUDITS ARE CONDUCTED FOR SOME TITLE 20 PROGRAMS WHILE LEAVING THE OTHERS TO YEARLY AUDITS.

I HAVE TRIED TO STATE SEVERAL PROBLEMS REFLECTED IN THE FRAGMENTAL FLOW OF FEDERAL HOME HEALTH MONEY. TITLE 21 CAN SOLVE MANY OF THESE PROBLEMS.

I THANK YOU FOR THE OPPORTUNITY TO PRESENT MY COMMENTS ON THIS IMPORTANT LEGISLATION.

The CHAIRMAN. Thank you, Mr. Batten. We will come back to you with questions when we have heard from Mr. Wessel.

Mr. WESSEL. Thank you, Senator.

I am Ken Wessel. I am the director of Visiting Homemaker Service of Passaic County in New Jersey. We are a paraprofessional service that deals mostly with homemaker/home health aides and we are subcontracted with by three visiting nursing services, such as my other panelists represent, in Passaic County.

There is a long established network of voluntary nonprofit homemaker/home health aide services throughout New Jersey. There is at least one agency in each county, 23 in all, dating back to 1952.

In 1979, these agencies provided 25,000 patients with almost 4 million hours of paraprofessional homemaker/home health aide services on a total combined budget of \$18 million. This with a total staff of 3,700 certified home health aides plus registered nurse supervisors.

In addition to medicare reimbursable home health aide services, many other community programs are offered by the visiting homemaker network. These include chore service, child abuse services, Meals on Wheels, social work, bath services, escort information and referral, et cetera.

Homemaker/home health aides have the training and experience to provide a broad range of care to families and individuals from the elderly person needing maintenance to remain at home to the mother who needs help with a new-born child.

Much of the emphasis, however, is placed on personal care for sick and elderly persons who would otherwise need expensive and impersonal institutional care. These services are provided very cost effectively with an eye toward the community's ability to pay.

The average 1979 fee for service was \$5.12 per hour. The large volumes of patients served is one reason costs remain low. Indeed, the mean fee for the four largest homemaker agencies in New Jersey was \$4.78 an hour, 34 cents less than the State average.

On the other hand, the fees for the four smallest agencies average \$5.99, 87 cents over the State average.

Clearly, it is in the best interests of the home care patient to maintain the system. It has a record of providing a diversity of qualified services at a low cost. In terms of Federal programs, this simply means more patients served per dollar.

There are several Federal and State policy initiatives that threaten the present system. Proposals that mandate that all home health aide services be provided directly by certified nursing agencies condemn the homemaker/home health aide agency without any added benefit.

If the medicare/medicaid caseload were removed from homemaker/home health aide agencies, their volume would be reduced by 60 percent. Survival would be unlikely and those other programs offered by these agencies would be lost to the community.

The cost of any services provided by any surviving agencies would be prohibitive due to reduced size. Home health aide services would become more expensive. The two homemaker/home health aide agencies in New Jersey that received certified status with medicare charge \$7.34 and \$7.25 per hour to their patients, more than \$2 over the State average.

If certified agencies could not subcontract for home health aides, they would be forced to turn away patients when staff became fully utilized. There is a national shortage of home health aides, but even if recruitment was not a problem, it takes weeks to train and orient new staff.

This proposal reemerged recently in reconciliation hearings. It must, once and for all, be exposed as shortsighted, expensive and not in the best interests of home care in general.

If quality of service is a problem in other States, national standards should be implemented for homemaker/home health aide agencies. National standards are in existence through the National Home Caring Council.

The majority of New Jersey's agencies have voluntarily sought and received approval under these standards. Another potential problem for homemaker/home health aide agencies, are the proposed caps on home health aide service based on visits.

A visit is not an appropriate measure for this type of service. Home health aides are assigned on an hourly basis, from 1 hour a day up to 8 and sometimes more. If a cap is set at \$32 per visit, would a home health agency be in a position to bill \$32 for a visit of 1 hour or 8 hours?

If the reimbursement is the same, regardless of cost and length of service rendered, might that not be an incentive to reduce the number of hours of care per patient while not affecting the charge to medicare? We simply suggest that the cap for home health aide services be based on hourly rates, or that a visit be defined in terms of hours.

In terms of pending legislation, we feel title XXI addresses many vital issues in the home care field and will provide maximum long-term care to noninstitutionalized elderly and disabled with minimum dollars.

It reduces fragmentation by providing one entry point and one funding source. It recognizes that the medical model is not the most appropriate for all long-term care services needed. This will keep costs down.

The bill accepts the separate identity of homemaker home health aide agencies and other essential home care services beyond medical care. By providing for tax credits for families that care for their own and by encouraging provision of respite care, XXI will stimulate more home care by families. The tax credits could be higher.

Perhaps some thought should be given to tying the credits to the difference between the dollar value of Federal benefits being received at home and the cost of institutionalization. To further maximize benefits with present dollars, we feel more prioritization is necessary within several programs.

Older Americans Act regs should be more specific in terms of the proportion of funds to be allocated to home care in each local AAA. Revenue sharing guidelines should be tightened so that fewer tennis courts are built and more elderly cared for.

As Federal funds get tighter, those who advocate for home care for sick and elderly must be more vocal. Hard decisions will have to be made to redirect funds from other worthy programs that are less essential.

Home care is most essential and cost effective. I am certain it will have competent advocates in the difficult Triage that lies before us. Thank you.

The CHAIRMAN. Thank you very much.

Mr. Wessel, you are all executives of service agencies. These agencies were created to respond to what is so clearly one of the harshest needs in life—when you are elderly and ill and need help. These are your clients, right? These are the people that you are in business for, and you are the executives of these agencies that can only be thought of as noble in purpose in meeting just such a fundamental and human need.

As executives of this kind of activity, let's start by having you tell us what are the things that just tear you up every day when you go to your work; tear you up because you know you are not reaching fully the needs that you are there to reach? What are your heartbreaking frustrations on your jobs?

Mr. WESSEL. It is frustrating because there simply are not enough funds to provide the diversity of service that everybody requires. Title XX funds are for people who are requiring home care that is not necessarily medically oriented, which includes a lot of elderly people who just need maintenance at home.

The CHAIRMAN. You know the people who are out there just desperately in need, but you can't reach them because of—

Mr. WESSEL. In Passaic County they stopped intake for title XX applications for home care through the Passaic County Board of Social Services last September because the amount allocated in title XX funds to them was clearly not going to last the year, and it was all they could do with an infusion of some title III Older Americans Act funds from the area agency on aging to keep services at a given level.

Only just recently, simply because of attrition of patients, have they taken on any additional patients. It was almost 6 months after we had no intake at all for title XX home care in Passaic County.

The CHAIRMAN. That left people without what particular services you saw they desperately needed?

Mr. WESSEL. In my case it was homemaker/home health aide services. Elderly people, often living alone, who couldn't function by themselves in that environment, needed someone to do shopping for them. Many of them were bed-bound. They needed somebody to prepare meals and encourage them to eat. They needed to know that somebody was coming once in a while, and that they weren't alone in the world.

It was and is a very essential service to a lot of these people. A lot of people were turned away. United Way gives us some money, but that was exhausted in 10 months, to help fill some of this gap.

The CHAIRMAN. Without your reaching this group, and, evidently a growing group because of the money pinch, what is their future?

Mr. WESSEL. If they survived at all there would be no alternative but institutionalization, nursing home placement.

The CHAIRMAN. Versus hospital admission?

Mr. WESSEL. Yes.

The CHAIRMAN. It results in the whole range of crisis response, because you were not able to reach them for orderly service care that would prevent the crisis.

Mr. WESSEL. One example this week, and it includes the title XX funds, was a family with a mother who has multiple sclerosis. She is in the later stages and is bed-bound. She has three young children who need care and a husband who has been trying to pay bills and work, and it is tearing him apart to see what it is doing to the children, trying to take care of this mother.

And he went to the Board of Social Services for some reimbursement for homemaker/home health aide services to come in as little as 2 hours a day to help prepare dinner so the children didn't have to do it.

The man was told he should not work, he should apply for Aid to Dependent Children. This way he would be eligible for medicare and medicaid, under its lower level of service, it might pick it up for home care.

Fortunately, we have some free care money from the United Way and we are able to pick it up for 2 hours a day, but the only reason we were able to free that is because other patients didn't need the help any more. But the community was willing to expend four times as much to put this family on welfare, with all of the social problems which that would have caused forever for that family, rather than spend very little for home care.

Senator BRADLEY. Senator Williams asked a question that I was interested in: When you can't serve people who are referred to you, what is the major reason why you are not able to serve them?

Mrs. CUCCARO. Lack of funds. We are in a little better position than Ken was here when our county welfare board ran out of title XX money. The Division on Aging was able to fund us a little further.

We have full-time aides on our staff at the agency, so it allows us flexibility in the utilization of them. While people may not have gotten two, three, or four service hours a day, everybody has something. But we have the same problem with the title XX funds. There just are not enough to go around.

Senator BRADLEY. If we adopted this approach in title XXI, what problems would remain for you?

Mrs. CUCCARO. Your priorities would have to be very, very specifically outlined. I think I could speak for all of us here. We are put under a lot of pressure by families to fill the families' wants, in relation to the elderly, rather than actually what the patients need.

I have been told many, many times over the phone that I am responsible for the elderly patient by the family members. Our experience with title XX this past year, when they ran out of money and everybody that was going to be cut off was entitled to a fair hearing, that was an assessment tool that was developed with a rating score on it, with our agency not knowing what the cutoff point was going to be.

The Division of Family Services made the final determination. We spent quite a few days in court hearings. The rating scale was reversed by a local judge based on some of the things the families told him about the patient.

If this is the kind of situation that is going to persist, nobody is ever going to do initial assessment and nobody is ever going to benefit from title XXI.

Mr. BATTEN. When I go in each day, the frustration I have is knowing that moneys are fragmented in little parts. Titles XVIII, XIX, XX—it requires our staff, if we are not providing those services directly, a great deal of time and effort in becoming advocates for the patient, either of senior citizens or otherwise, to find those resources.

Many times they are provided by other agencies in the community and my point is that they have grown up over time because the funding in the Federal Government has been very different and comes from different sources. I think that is the general frustration I have.

I think the second thing—I heard it recently stated that title XVIII and medicare were for home health services—is that medicare was not developed as a part of home health services, and I think we have an institutional bias in the reimbursement system and home health is only one little part down at the end, and no one ever thought about how it would be financed with all the add-ons into all other systems. Title XXI I think, gives us the tremendous opportunity to say, “OK, if we are really going to be strong and viable in the community we need to think about funding it in a uniform manner that doesn’t force us to spend a lot of time and money in hidden and administrative costs, in nursing costs, and telephone costs just to find Meals on Wheels,” et cetera. So that is an ongoing frustration.

I think, to answer Senator Bradley’s question, the biggest problem we find is that we are the last spot for noninstitutional services. People go through the system, and we take care of them under title XVIII, and we get them to a point where we are going to rehabilitate them to the best that they are ever going to be.

They are age 80 and they are never going to be able to make it without a wheelchair or a walker, but they are not going to be able to make it by themselves any longer either and the alternative is a nursing home. There just is not the money available as an alternative.

The State of New Jersey has expanded their medicaid title XIX program, but there is a frustration that we have a different eligibility level, and they are going into nursing homes at a higher level than we can take care of them at home.

And those working poor are the people we see all the time, and we try to do the best we can with the limited moneys we have. United Way moneys—we have all talked about it—is about the only source that we see for the working poor, the people just above medicaid, and those are the ones that we cannot do enough for.

Mrs. CUCCARO. I would like to make another comment. We have seen the “revolving door syndrome” become a greater problem because we are discharging patients, then they go back into the hospital in 4 days, and come back out.

The condition has not changed basically. They come back out thinking they are going to get back on medicare again. Looking at the statistics in my agency, the readmission rate is tremendous. When we think of all the paperwork involved in this whole read-

mission procedure that you have in an agency, it is very frustrating.

I think the other thing you have to remember is that when we talk about taking care of the elderly we are talking about elderly with chronic illnesses which could become acute at any particular day of the week.

This is why you need that ongoing monitoring of these patients, whether it be with title III funds, title XX funds or municipal funds. They are fragile people whose condition is liable to worsen at any particular time.

If the monitoring is there you can very well prevent hospitalization for an acute illness.

The CHAIRMAN. It seems to me that you spend such an inordinate amount of administrative time as accountants on just which particular program you must look to for reimbursement.

Mrs. CUCCARO. Could you see us explaining to nurses who are concerned about nursing care about 70 different sources of funding we have within the agency and how they use which one?

Senator BRADLEY. No, I can't. Mr. Chairman, I am going to have to leave and I just want to express my appreciation to you and to this panel in particular for their testimony. They have made a very important contribution from my perspective because they are out there every day trying to deliver homebased services.

The CHAIRMAN. It has been most revealing from where I sit too. I knew there was administrative complexity and program difficulty the way we have arrived where we are in a hodge podge, really, of responses. And that is why we are trying to find the simplifying solutions and then reach a broader population that is out there in need.

Your help is absolutely essential in finding our way through the maze and out to the end of the line where we can offer a much better approach to serving the needs we are talking about. You are absolutely essential. We thank you and we hope to be able to stay in communication because this is only the beginning of our response. We are well on the way but we need more and more from your background and experience.

Senator BRADLEY. Mr. Chairman, would it be all right with you if I did submit questions for the other witnesses?

The CHAIRMAN. Yes, fine.

We are going to take a 5-minute recess and return.

[A recess was taken.]

The CHAIRMAN. If we could reassemble, please.

Welcome, Dr. Bruce Vladeck.

If Thomas Russo and Barbara Sigmund want to come up and join at the table at this time. This is our next group of witnesses.

Dr. Vladeck, I haven't had a chance to read your statement but I appreciate the fact that you have presented it to us. It will be made part of our record and you may proceed any way you want to.

STATEMENT OF BRUCE VLADECK, ASSISTANT COMMISSIONER, NEW JERSEY DEPARTMENT OF HEALTH; THOMAS M. RUSSO, DIRECTOR, DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES, NEW JERSEY DEPARTMENT OF HUMAN SERVICES; AND HON. BARBARA B. SIGMUND, DIRECTOR, MERCER COUNTY BOARD OF CHOSEN FREEHOLDERS, A PANEL

Dr. VLADECK. Thank you very much, Senator. I very much appreciate the opportunity to appear here.

The CHAIRMAN. I didn't give your full designation as assistant commissioner, health, planning and resources development in the New Jersey State Department of Health.

Dr. VLADECK. I am now able not to repeat that. I did have a prepared statement and in view of the hour and that it also reads like a prepared statement, let me just say a few things very briefly and I am, of course, happy to respond to any questions you might have.

I think there are three things that I would like to say primarily. The first is that there is no question but that there are many people who are now either at risk of being placed in institutions, or at home being inadequately served, or in hospitals being inadequately served who could benefit in a very cost effective way from expanded availability of in-home services.

I think the second thing to be said is, to really repeat the point that has been raised a couple of times today, we are not yet confident—at least from the viewpoint of us bureaucratic public officials—that we have a mechanism to ascertain just which individuals are out there who are more effectively served inhome than they are by nongovernmental programs, or in the institutional services.

So, the third thing that is really the central point I would like to make is that we have got a history now of 25 years under medicare and medicaid of seeking to expand individual services reimbursed on a fee-for-service basis, one at a time, in a way that over time creates not only cost problems but all of the fragmentation and coordination problems mentioned by the previous panelists.

It seems to me essential that if we are going to have a services system that responds to the needs of the clients rather than to public categories of one kind or another, then it really is essential to have some central mechanism such as that described in the Packwood-Bradley bill, such as that toward which other proposals have moved, such as that being tested in the channeling demonstration project.

There can be a single entry point that can be responsible for assessing and coordinating services which I would think should be responsible for general oversight of the funds involved.

In the absence of such a mechanism, as long as we remain on a decentralized fee-for-service basis, we can't be confident that we are going to be cost effective; we can't be confident that people are going to be supplied with the services that they can make best use of; we can be certain that the service providers are going to be sufficiently responsive to the very rapidly changing and often hard to put your finger on needs of the very ill or very frail elderly whose needs tend to be very complicated and to change very dramatically over time.

So, just to quickly sum up, I think there is no question, no one is arguing that we need a substantial expansion of home health services. The real problem, and I am not sure that intellectually it is such a hard problem, is to find the appropriate administrative or organizational mechanism that can be responsible for providing the appropriate match between client needs and service deliveries, and at the same time, through any number of possible mechanisms, be responsible for the kind of budgetary control that permits you to be confident you haven't just created another open ended entitlement which 5 years from now or 8 years from now we will be worried about cutting costs of.

[The prepared statement of Dr. Vladeck follows:]

Statement of Bruce C. Vladeck, Ph.D.
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Before the Committee on Human Resources
United States Senate
Hearing on Home Health Care
Princeton, New Jersey

November 23, 1980

Mr. Chairman, ladies and gentlemen, my name is Bruce C. Vladeck. I am Assistant Commissioner for Health Planning and Resources Development, New Jersey State Department of Health. It is a great privilege and honor for me to be invited to appear before you today to participate in your hearings on the critically important subject of home health services. I think the very fact that these hearings are being held, in conjunction with the Governor's Conference on Home Health Care, to begin later today, appropriately signifies an interest and concern on the part of our elected officials in this most central issue in the future of the delivery of health care services to many of the most needy members of our population.

I should begin by clarifying my role in appearing here before you today. While, as Assistant Commissioner of Health, I have a number of responsibilities in the area of health planning, and while everything I will tell you today is consistent with the policies of the Department and of the State Government more generally, I should emphasize that I am speaking primarily of my individual views and opinions in these matters. In that regard, I suspect that some activities of mine completed prior to my joining State Government, specifically research I had done on long term care when I was at Columbia University, which resulted in the publication earlier this year of a book on long term care entitled Unloving Care: The Nursing Home Tragedy, may have had as much to do with your most generous invitation for me to appear as my formal position.

I want to especially emphasize that I can not claim to be enunciating the systematic, comprehensive policy of New Jersey State Government for home health services. And I say that with some pride, because I would like to begin the substance of my remarks by describing to you very briefly some rather extensive planning activities now being undertaken within State Government towards the development of comprehensive,

policy-specific plans in the areas of long term care and home health services.

As you may know, the State Legislature recently enacted a bill, S.B. 373, which calls for creation of an Interagency Task Force on Home Health Services, to be comprised of representatives of the Departments of Human Services, Community Affairs, Health, and Insurance. That Task Force is to make specific recommendations, based on its findings, to the Legislature for appropriate action. At the same time, New Jersey, as I'm sure you are well aware, is particularly proud of having been one of the fourteen states to receive Federal contracts under the National Channeling Demonstration Program to create a model demonstration project in the coordination and case-management of a comprehensive mix of long term care services, obviously including home care. A major part of the State's responsibilities under the Channeling Demonstration Project is development of a comprehensive State-wide long term care plan. I am privileged to sit on the Steering Committee for that planning effort, and I am confident that within the next year the agencies involved, supported by the additional staff made available through the Federal contract, will develop a far-reaching, systematic, and comprehensive set of objectives and proposals which can help guide State policy-makers in the development of better means of meeting the needs of our frail elderly and disabled population for the balance of this century. Therefore, when I say that there is no specific State policy which I can enunciate, that is because we are very much engaged in devoting considerable effort to the formulation of a far more systematic and comprehensive set of policy directions than has ever before been available in this State, most other States, or quite frankly, at the Federal level.

Even prior to the completion of our comprehensive plans for home health and long term care services, I think I can share with you a number of propositions and assumptions in which I strongly believe, and which I believe are widely shared among my colleagues in State Government. These would form the basis for the specific comments and recommendations I will make later in my statement, and will also undoubtedly serve as the touchstones for our planning efforts.

First among these is our general belief that in-home health and health related services are very often the most desirable way of meeting the health and health related needs of large numbers of persons with both acute and chronic problems. Second, we believe that there is currently inadequate access to such services among many of those who might benefit from them, and that such inadequate access often leads to inappropriate and very expensive reliance on institutional care. But third, if we are to learn anything from the unsatisfactoriness of our current experience, it is that the design of better services must be grounded in an assessment of the full range of needs of the people we are seeking to serve, and not in the ad hoc, piecemeal expansion of one service at a time, especially if that service is to be reimbursed on a fee-for-service basis.

In other words, Mr. Chairman, the central message I would like to communicate to you today is that there is no one answer to the needs of all of our frail elderly and disabled citizens, nor is there any single service which provides a magical panacea for the many problems we now encounter. If we are in trouble today, it is in part because in the past we have attempted to respond to the very difficult and complex problems of dependent people with disabilities of one kind or

another by expanding one or another particular service. What we must do in the future is to expand our capability to bring to those in need an appropriate mix of services that are responsive to the characteristics of individual clients and sufficiently flexible to adopt to changes in the client's conditions and needs.

There is no question but that, for many individuals experiencing many kinds of problems, health and health related services delivered in the home are more cost effective and more efficacious than similar services developed in an institutional setting. Under proper administrative and supervisory management, many people who would otherwise end up in institutions can be maintained in a more home-like environment at less cost to public treasuries. Further, and this is a point which advocates of in-home services often downplay but which must, if we are to be honest about our problems, be specifically addressed, there are many instances in which in-home services are no more effective or more efficacious than institutional services, but are preferred by clients or by policy-makers on the general policy principle that individuals should be able to reside in the least restrictive environment in which they can successfully function.

There has been substantial controversy over the years as to whether or not, in general, in-home services are cheaper and better than institutional services. Precisely the nub of our problem, I would suggest, is that there is no single answer to that question, that the relative desirability of institutional as opposed to in-home services, and the relative appropriateness of a range of in-home services, vary substantially from one potential client to another, and for any given client over time. I believe we are at the point where we have to begin to make our service delivery patterns more responsive and more capable

of adapting to the needs, especially the changing needs, of service clients, rather than expecting those clients to fit into one or another categorical boxes. In that context, substantial expansion of in-home services, especially home health services, is agreed by almost everyone to be a necessary component of an improved system of long term care for the frail elderly and disabled. But it is only within that context that we should support such an expansion. That is why we so eagerly submitted our application to participate in the Channeling Demonstration Program, and why we are so pleased to have received a Channeling Award. It is also why I have argued, and will continue to work, for the development of a State-wide long term care plan which does not address the needs for long term care on a service by service basis, but rather begins by looking at the needs of the clients, and then seeking to develop appropriate administrative mechanisms to match clients and services.

These rather abstract-sounding considerations in fact have critical importance when one begins to look at the unavoidable question that policymakers must always confront, that of costs to both public and private programs in a period of increasing resource stringency. I do not believe we can afford, under current circumstances, to simply embark on an expansion of any given services on the expectation, no matter how well grounded that expectation may be, that such an expansion will substitute for or replace existing patterns of care. Rather, we should expand services such as home health and other in-home care under the aegis of mechanisms which can assure us that substitution will take place, and that budgetary control is insured before we get underway. Such a mechanism, for example, would be that contemplated under legislation introduced by Representatives Waxman and Pepper earlier this year, H.R. 6194, which would provide Federal financial participation in Medicaid payments

for a mix of non-institutional services when it was determined that a client would otherwise, in terms both of financial eligibility and medical need, qualify for Medicaid reimbursed nursing home services, and when the total cost for non-institutional services would not exceed that of nursing home reimbursement. A similar model has been provided by the so-called "Nursing Home Without Walls" program in New York State. And of course, the same general principle underlies the legislation introduced earlier this year in the Senate, and co-sponsored by both of our New Jersey Senators, to create a Title XXI to the Social Security Act.

I have no illusion that the general point I am trying to communicate is new to any of those in the room. I am simply trying to express my strong concurrence with the basic principle that, if we are to expand the availability of home health and other in-home services, we must not repeat past mistakes in the design of social programs, but rather address at the outset appropriate administrative and managerial concerns.

Of course, everyone involved in the process has recognized that both the Title XXI proposal and the Waxman-Pepper Bill represented the sorts of far-reaching and long-range policy innovation which often require years of Congressional consideration and deliberation, and which are unlikely to be enacted over night. Anyone privileged to appear in a context such as this bears some responsibility to also comment on shorter-range and more immediate things we can do, since the hundreds of people who today are awaiting placement in long-term care institutions, and the hundreds more lying in hospital beds because of the unavailability of appropriate services in the community, can not be

expected to wait until some distant future for help in meeting their needs. In this context, there are several comments I would like to make. You will find none of them radically new or particularly different from what you, Mr. Chairman, and other members of the New Jersey delegation to the Senate and House have consistently supported, but I suppose it can't hurt to make them anyway.

I do believe it makes perfectly good sense to remove the three-day prior hospitalization requirement for receipt of home health benefits under Medicare. If anything, all this requirement now does is provide an incentive for physicians and others interested in the care of the frail elderly and disabled to generate unnecessary and costly hospitalizations.

I do believe we should continue to support, both through grants and through the development of greater training and technical assistance capabilities, improved management and administrative capabilities for existing voluntary home health and homemaker agencies. Many of these agencies, which embody a long and noteworthy commitment to selfless service of the public good, will be incapable of responding to the challenge posed by the inevitable expansion in financial support for home health services unless we continue such programs.

I do believe we should continue to support experiments and demonstrations in the community-wide financing, on a capitation or other basis, of a range of services tied to the needs of individual long term care clients. Such demonstrations could follow the lines of the so-called "Social HMO," of more conventional Health Maintenance Organizations, of the very successful Triage channeling Project in Connecticut, or other models.

I do believe we should provide greater incentives to State Governments to equalize eligibility standards for long term care between institutional and non-institutional clients, along the lines contemplated in proposed legislation. Ideally, of course, the states would undertake such equalization without additional Federal incentives, but as I'm sure you are aware, current fiscal realities in New Jersey and elsewhere make this simply impossible without assumption by the Federal government of a somewhat greater share of the overall cost.

Finally, I think we have to begin to do a much better job of encouraging institutional providers of health care, especially our hospitals but also our long term care facilities, to see themselves not solely as institutions confined within a given structure of bricks and mortar, but rather as responsible for the health care needs of a broader constituency, without as well as within institutional walls. Thus, we need to find better mechanisms to encourage such institutions to develop either their own home health services, or, more likely in most instances, far better and more supportive linkages with those agencies providing services to people in the community.

Mr. Chairman, in the next twenty years the population at risk for long term care services will double. As a society, we can not afford to maintain the status quo in public policy for health services to the elderly and disabled. Simply continuing to do what we are now doing will bankrupt us before very long. More importantly, from the point of view of simple humanity, we can not continue to ignore either the crying needs of many people who are now being inadequately served, nor the increasingly strong body of evidence that what they need is no mystery, but rather simply a better set of administrative mechanisms through which we can promote a very substantial

expansion of often relatively simple services to people where they live. I believe that the very presence of these hearings today represents a recognition of the pressing need to begin to move in this direction, and I am pleased to have had the opportunity to participate in it.

Again, I am grateful for the opportunity to have appeared before you today. I would, of course, be happy to respond to any questions you might have.

Thank you.

The CHAIRMAN. When I joined in the Packwood bill I joined with the hope that we might find a way to create an administrative situation where all the services that can be delivered to the people who need them in their home, can be from one funding stream rather than XVIII for a while and then jump to XX or XXI.

Right now, anyone who needs support in order to live at home has to be almost a program analyst to know where to go. We are trying to administratively centralize and also, as part of that centralization, to have some channel for funding through one mechanism. Does that make any sense to you?

Dr. VLADECK. Senator, I would suggest that we should go further. It seems to me that one of the most successful of the demonstration projects around, and one that I think might be the best model, is the Triage project in Connecticut.

As a single entry and funneling point, Triage controls not only funds for in-home services but medicare hospital funds, medicare physician reimbursement, expanded medicare drug coverage, the whole spectrum of services.

A large part of the problem with both nursing homes and hospitals is that the big dollars are in those places and the community hospitals don't have to respond to anyone in the social services system. They sit up on their hills, isolated, creating problems for everyone else in terms of their discharge planning, or their failure to provide certain services in the community. Yet, those are where the big dollars are flowing and I would recommend seriously for your consideration that if we are going to have an agency such as that proposed in title XXI for clients who are identified by the PAT or some similar mechanism as in need of long-term care, that we ought to give that agency responsibility for the whole range of covered services, not just in-home services but covered in-institutional services and perhaps even covered physician service.

The CHAIRMAN. That is not encompassed. What I suggested is clearly within the formulation of S. 2809, the Packwood bill.

Dr. VLADECK. As I understand it, I don't think there is anything wrong with that and I would support it.

The CHAIRMAN. You would just make it more comprehensive?

Dr. VLADECK. But I think it should be more comprehensive still.

The CHAIRMAN. I get you. We have our own problems, administrative problems.

Freeholder SIGMUND. May I ask a question, Senator?

The CHAIRMAN. We have got five committees involved.

Dr. VLADECK. I am aware of that.

Freeholder SIGMUND. Since you kindly said this might be a panel type situation, may I ask a question of my fellow panelists in that regard.

The CHAIRMAN. Yes.

Freeholder SIGMUND. I am here today as the president of the Mercer County Freeholder Board and the first vice president of the New Jersey Association of Counties, and one of the points that I really wanted to make very strongly today is that at least in New Jersey—as you know, not by any rational State-directed plan—the county governments have had to become the providers of long-term services in nursing homes in New Jersey one way or another.

It has grown like topsy. It has absolutely no rationality to it whatsoever. I assume that one of the reasons I was graciously invited to come here today was to speak to that experience from the point of view of a working county official and to talk about some of the things we would think would make sense as alternatives or intermediate steps of care to the growing demand for the nursing home beds that we simply could never provide.

I have Dr. Vladeck's articles, even the New York Times Op Ed page on the same subject. I would suggest, when you are thinking about mechanisms for coordination that you think about the 3,000 county governments that already exist in the United States that, in essence, have been faced with this problem for many years on a daily basis and might best be used as the coordinators of all these services.

Dr. VLADECK. If I may respond to that very briefly, if we are going to give some kind of agency or administrative entity what is essentially the power to control the distribution of dollars to people in need, I think it is imperative that those agencies be accountable to the general public and accountable to their client personnel in a way that, unfortunately, many groups of physicians, for example, that have been responsible for control of certain funds, aren't.

So, I think some kind of public accountability—I don't want to be put in the spot of the State official saying it should always be the county—but some kind of mechanism that insures that sort of public accountability would seem to me very important.

Mr. Russo. Senator, I am Tom Russo. I am the director of Medicaid in the State of New Jersey. I also wear another hat in that I am the Secretary and a member of the executive committee of the National Association of State Medicaid Directors who spend some time addressing these issues as well.

The objectives sought out in the Packwood bill and proposed title XXI are laudible. However—and I made mention to it in my prepared text—what it does is create another fragmentation in the health—so-called—nonsystem.

It sets up another mechanism to deal with issues that currently are being handled under various other titles, and it will set up a whole new bureaucracy to administer a title XXI, if that comes about.

And you will still have the fragmentation that you have today and you will still only be addressing part of the problem. It would seem to me that before we create another title, whether it be XXI or some other title, that we ought to really take a good, long look

at the existing title and see how it might be expanded or modified in some way to address some of these issues that we have been talking about.

A change in some simple definitions, in some of the titles, might go a long way to expanding the services that are now available. I think we want to be leery of creating another bureaucratic layer that really is not going to resolve all of the problems, and we are still going to have the fragmentation that we have at the present time.

What we need to do, I think, is look at the existing titles and see how they may be amended to meet some of our objectives. But, then, going beyond that, I think we in this country have to develop a national philosophy on health and the aging. We really don't have a national philosophy.

What do we want to do within the next one or two decades in this area? We know what the demographics are. We know what the census projections are. We know how many elderly people there are going to be in this country in 10 years, in 20 years. But what is our philosophy for dealing with them?

I think we need to address that issue and then when we address that issue to try to develop legislation and administrative ways of dealing with it. One of the things that we have to really avoid is the break up of families.

The present system that we have now, with all the multiple fragmentations and the funding sources, is breaking up community families in order to provide services and we should not be doing that. We should not be breaking the families up.

We should be looking to give families greater support than they have now and provide the kinds of home health care and multiple services that they need, keep them in the community to the maximum extent possible.

[The prepared statements of Mr. Russo and Mr. Reilly follow:]



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STATEMENT

BY

THOMAS M. RUSSO

DIRECTOR
DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES
NEW JERSEY DEPARTMENT OF HUMAN SERVICES

ON

HOME HEALTH AND LONG TERM CARE PROGRAMS

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES
AND THE
SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

SUNDAY, NOVEMBER 23, 1980

MR. CHAIRMEN AND MEMBERS OF THE SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES
AND THE SENATE SPECIAL COMMITTEE ON AGING,

I am Thomas M. Russo, Director of the Title XIX Medicaid program in New Jersey.
Thank you for the opportunity to speak to you today about home health and long
term care activities from a New Jersey prospective.

As you know, the issues being discussed today have been the subject of increasing
concern over the past several years and will take on greater significance within
the remaining two decades of this 20th century. During that short span of twenty
years, we will see a significant increase in the number of aged persons in this
country, with a corresponding extension in the number of years of life expectancy.
Nationwide, the number of persons over 65 is expected to increase by 6,900,000
individuals within that time, while in New Jersey alone, that increase will include
332,000 persons. Government activity at all levels must gear up to the multiple
problems that will confront us because of this simple but significant change in
the population distribution.

We must develop an overall national philosophy for the aging and must then implement
that philosophy by administrative and legislative action. We should not fool our-
selves into thinking that this will not cost money, because it will. However, it
seems to me that we are mandated to consider and address both the health and social
care needs of this growing part of our national census.

We must take a long hard look at our institutionalized elderly, both in health
care and residential care facilities and must recognize and implement programs to
minimize that institutionalization to the maximum extent possible. We must recognize
the integrity of family units and of individuals who live alone without family support

and make available a community service network which will encourage continued community living.

We are, of course, talking about such services as home nursing, homemaker, home health aides, chore services, home attendants, home handymen and personal care workers. In addition, we must consider such related programs as congregate housing, community mental health centers, foster care for adults, and social/medical day care activities. Maximum effort must be made to keep an individual at home or in a community living unit by providing the outside support that is necessary. To accomplish this, I suggest that your committees and the Congress seriously consider a program of tax supports and/or subsidies for such individuals and their families. These would provide much needed incentives and financial support.

As a first step, the Federal Government must develop an overall philosophy with objectives to meet these needs of our elderly and disabled. At the present time, we have such programs as Title 3 Older Americans Act, Title 18 Medicare, Title 19 Medicaid, Title 20 Social Services, and a proposed Title 21, which would unite community based care and funding provisions under one program. Under these existing programs, including the proposed new one, we have a fragmented delivery of health care and social services from various funding sources which essentially address the same needy population. The objectives have been laudable but the fragmentation and overlapping have caused enumerable problems and have in some instances impeded the full realization of the objectives. Title 21 represents another laudable effort to address these needs, but does so by establishing another potential layer of government bureaucracy and fragmentation of a non-system.

I think we need to honestly address this fragmentation and the current Titles funding health and social programs for the aged and attempt to amend the current Titles rather than create additional fragmentation.

Current standards of eligibility for Medicaid supported community health services are so restrictive in states without a medically needy program that they prohibit the full realization of access for community related programs, such as home health care. It is of utmost importance that these eligibility standards, which have a pro-institutional bias, be changed to permit states on a voluntary basis to increase the community eligibility threshold up to the level of institutional eligibility standards. H.R. 6194, the Medicaid Community Care Act of 1980, would provide Medicaid reimbursement for a wider range of home care services than is currently permitted. We urge continuing support of that objective. Mr. Gerald J. Reilly, Deputy Commissioner of the New Jersey Department of Human Services, this past summer, submitted a statement on H.R. 6194 to the Subcommittee on Health and the Environment of the House Committee on Interstate and Foreign Commerce. Rather than reiterating his statements in this presentation, I have chosen to append a copy of his full text as an addendum.

Mr. Reilly, on May 22, 1979, also testified on this issue before the Subcommittee on Health of the Senate Committee on Finance concerning Medicaid home health benefits. At that time, Mr. Reilly said "Title XIX should be amended to, in certain situations, equalize institutional and community eligibility standards so that persons who might otherwise be institutionalized can remain in their own homes when it is cost effective to do so. Under current Medicaid regulations,

persons having up to \$568 (\$714 as of July 1, 1980) in monthly income may receive Medicaid nursing home care, but may not receive Medicaid home health services unless their income is below the SSI standard. We propose that, for persons medically determined to require institutional care, Medicaid eligibility for home health services should be made equivalent to the institutional eligibility ceiling of \$568 (now \$714) per month. Once determined eligible, the person would pay a certain percent of his income toward the cost of his home health services."

Today, for example, a person can be Medicaid eligible in New Jersey if his income is less than \$714 per month. However, such a person living alone who could benefit from home health or medical day care services would be eligible only if his income was less than \$261. With this difference, it is not hard to see that it becomes extremely difficult to discharge a person to his home with community supports. A copy of New Jersey's Resources and Income Standards is attached.

The fragmentation of the funding sources of existing programs has forced states to develop ways to maximize the use of funding sources for needed health and social service programs. This has required a delicate balancing of service definitions which, undoubtedly, vary from state to state with a similar program in one state being reimbursed by Title XIX as a health care program, while in another state, the same service is being reimbursed under Title XX as a social service program. It should not be necessary to juggle definitions to obtain Federal matching funds. Mr. Reilly addressed this issue before the Senate Subcommittee on Health and suggested that "Federal financial participation in the full range of home care services for low income persons should be provided through

a single funding source such as Medicaid. The medical orientation of Title XIX home health services precludes maintenance of the individual in the community without supplementary social and personal services derived from other sources. If one of these support services is disrupted, the home care recipient is often forced to enter an institution. Single source funding of a full range of home health related services will overcome the current fragmentation, and in many cases, may prevent or delay the use of more expensive institutional care."

The Department of Human Services continues to support these positions outlined by Mr. Reilly. For further enlightenment, I have also appended a copy of his testimony at that time as an addendum to this presentation.

In a recent survey of Medicaid Directors in the various states, the states were asked what changes they would propose in Federal legislation and/or regulations to allow them to meet the needs of their long term care populations. Most of the states indicated that incentives for institutional care must be eliminated; conversely, incentives for the utilization of alternatives to institutionalization must be initiated. Approximately 25% of the respondents suggested that Federal Financial Participation be introduced for lower level facility care. Approximately 21% of the states indicated that they would like the scope of reimbursable home health care services to be expanded. It was proposed by about 13% of the respondents that the Federal Financial Participation level for home health care services be increased.

In the same survey, many states suggested mechanisms for increasing eligibility and recommended that the income level for home health care eligibility be increased

to that of institutional care. Other suggested proposals to expand eligibility included repealing the "homebound" and "skilled nursing" requirements of the Medicare program and eliminating Medicare's three-day prior hospitalization requirement and 100 visit per year limit. I believe some of these recommendations are contained in the Reconciliation Bill now before the Congress.

As you probably know, the Health Care Financing Administration of the U.S. Department of Health and Human Services has recently approved a total of 12 long term care channelling contracts to study various methods of providing community care services with the objective of assisting informed support systems in the community as alternatives to institutionalization. It will be a number of years before the results of the demonstration projects are known.

Although these programs are a valuable adjunct toward the development of a long term care philosophy, I do not believe that we should wait for such initiatives, but that we should move forward at this time to support and enact the changes that have been mentioned in this presentation. The problem with many Medicaid waivers and demonstration projects is that they may prove beneficial, but few, after their expiration, are permanently put into place. The two basic reasons they are not implemented are the lack of available funding at the State level for continuation of the programs and the fact that once the waivers have expired, it is almost impossible to obtain Federal approval to continue the programs because they do not fit into the mold of existing regulations. As a result, most often, the demonstration projects end up being academic exercises that cannot be implemented. There must be

changes in this area at the Federal level so that workable and effective projects can be continued and bring about necessary system changes.

Although it is obviously impossible to address all of the issues relative to the topic of this presentation, I believe I have outlined some of the more immediate concerns that we have in New Jersey. In closing, I would suggest that serious consideration be given to establishing a White House Conference on Health to focus on health care, including long term care and home health program issues, similar to those conferences which currently exist on the aging and for family and children. I believe that the initiation of such a Conference would begin to focus on a more unified and national approach to the growing concerns in this area and would help to develop an overall governmental philosophy to be followed. Such a Conference appears essential if the United States is to realistically and totally develop a rational and workable system for the elderly in the decades ahead and to avoid the fragmentation and gaps in service delivery that exists today.

Thank you again for this opportunity to express New Jersey's views.

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STATEMENT ON H.R. 6194

"The Medicaid Community Care Act of 1980"

before the
Subcommittee on Health and the Environment
Committee on Interstate and Foreign Commerce
U.S. House of Representatives

by

Gerald J. Reilly
Deputy Commissioner
New Jersey Department of Human Services.

STATEMENT ON THE MEDICAID COMMUNITY CARE ACT OF 1980
(H.R. 6194)

The State of New Jersey is committed to the implementation of a needs oriented long-term care delivery system. We envision a system that addresses the needs of all groups such as the elderly, disabled, mentally retarded, handicapped and the mentally ill. The system will make available to those groups the services that will allow them to continue functioning in the least restrictive appropriate environment. The system must provide a continuum of care ranging from a skilled nursing facility at one end to independent community living at the other. We wholeheartly support H.R. 6194 as a significant step designed to make such a system a reality.

Although unintentional, the current Medicaid program is biased in favor of institutional rather than community based care. In FY 1979, there were about 25,000 elderly (65+) residing in nursing homes in New Jersey. Among those residents, about 22,000 were in intermediate care facilities. In 1977, a study conducted by the Urban Health Institute for the New Jersey Medicaid program, found that 35% of level IV(B) intermediate care residents could have received appropriate care in the community if adequate social and medical services had been available. In FY 1979, about 5,400 aged residents in intermediate care facilities were level IV(B) patients. If 1,900 (35%) of those patients had been treated in the community, the critical shortage of nursing home beds in New Jersey could have been reduced by 50 percent.

In its present form, H.R. 6194 represents a significant step at the Federal level, towards addressing the bias in favor of institutionalization inherent in the Medicaid program. However, we would like to suggest several items that would foster greater utilization of home health care and would better integrate such services into a rational chronic care system.

First, the social security act should be amended to provide Federal financial participation in the full range of home services so that there is a single funding source for eligible people.

The fragmentation of funding sources and providers is frequently cited as a barrier to the utilization of home health services as an alternative to institutionalization. The medical orientation of Medicaid home health services precludes maintenance of the individual in the community without supplementary social and personal services derived from other sources. Fragmentation of funding tends to foster fragmentation at the point of service delivery. For example, a single Medicaid recipient might receive medical services

from a home health agency, homemaker services from a Title XX contractor and nutritional services through a meals-on-wheels program. If any of these services is disrupted, the well being of the individual could be jeopardized.

Although H.R. 6194 provides additional funding for home health services, the following services are not included:

1. social day care service
2. chore service
3. transportation service
4. recreation and socialization services
5. legal services
6. meals-on-wheels service.

Some of those services are funded under Title XX, a close ended program, and would be eliminated if funds are expended.

Programs providing home health services to an individual may often have different eligibility criteria and service standards. This fragmentation of programs and services hinders the implementation of the basic core functions of a long-term care system; i.e., case finding and screening, comprehensive needs assessment, case management and service audit and program review.

In order to reduce the problems associated with fragmentation, we recommend that medical and social home health services be provided as covered services under H.R. 6194. If this were done, there would be an incentive to use Medicaid as a single funding source for home health services rather than a combination of open and close ended programs.

Second, H.R. 6194 should allow states, at their option, to provide home health services to eligible people who are in potential need of long-term skilled nursing or intermediate care services.

In its current form, H.R. 6194 will provide Federal financial participation, at the increased rate, for comprehensive assessments and home health services for those individuals determined to be in need of long-term skilled nursing facility or intermediate care facility services.

It is estimated that there are 800,000 elderly (65+) in the state of New Jersey. Under our current long-term care system, about 20 to 25 percent of those elderly will need nursing home care at some point in their lives. In New Jersey, about 8.2 percent of the elderly qualify for services under the current Medicaid program. Many of those individuals could remain in the community longer, or maybe not need skilled nursing care at all, if home health services were available before their health condition deteriorated to the point that nursing home care is required.

According to a GAO report to Congress; Home Health -- The Need For A National Policy to Better Provide For the Elderly, December 30, 1977, "until older people become greatly or extremely impaired, the cost for home services, including the large portion provided by families and friends, is less than the cost of putting these people in institutions." We believe the need for institutionalization would be further reduced if comprehensive assessments and home health services were provided for certain eligible elderly people that might need long-term skilled nursing facility or intermediate care facility services in the near future.

Third, H.R. 6194 should recognize medical social work as a covered benefit under the bill. There is significant documentation to show that, to enable an elderly or a disabled person to maintain or to move towards independence, there must be a well integrated system of health and social services which will provide supportive care in a variety of settings as the individual's needs change. Since Medicaid is the major funding source of long-term care for the elderly and disabled, medical social work should be included as a covered service under the program.

Under H.R. 6194, it is unclear if medical social work is a covered service. To ensure that the services are uniformly provided nationwide, medical social work should be listed as a covered service under the bill.

Fourth, H.R. 6194 should allow states to phase in implementation of the program and initiate a co-pay system.

Medicaid expenditures in New Jersey, as in many other states, have been increasing significantly. Because of the costs of the current Medicaid program, the many required services that must be included, and the requirement to implement statewide, we have been unable to fund a medically needy program.

We are concerned that if H.R. 6194 was enacted, we would be in the same situation of not being able to implement a worthwhile program because of insufficient state funds.

Because we do not have a medically needy program, we have an especially great need to provide home health services to individuals whose incomes are above the community Medicaid eligibility level but below the institutional level. Implementation of H.R. 6194 will be more costly in states without medically needy programs because those individuals currently receive no services under Medicaid. States like New Jersey should be permitted to phase in implementation of the program on a geographic basis to reduce the initial cost of the program.

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States should be also permitted to establish a co-pay system for individuals whose incomes are above the community normal Medicaid eligibility level. Currently these individuals do share in institutional expenditures and therefore should defray the cost for community care as well. For example, providing full Medicaid coverage to individuals whose incomes equal \$700 a month, without their sharing in the costs for care, seems excessive. Initiating a co-pay system would also discourage unnecessary utilization of services and therefore could be a useful cost containment measure.

The items we have outlined are Federal financial participation in the full range of home care services through a single funding source, the availability of home health care to individuals prior to their needing services at skilled nursing homes and/or intermediate care facilities, the inclusion of medical social services under H.R. 6194 and allowing states to phase in implementation of H.R. 6194 and initiate a co-pay system. These proposals comprize logical steps leading to the implementation of a continuum of care long-term care model operating on the principle that people are entitled to receive care in the most appropriate, least restrictive and cost effective setting.

400 Resources and Income

480. TABLE A

Variations in Living Arrangement	Medicaid Eligibility Income Standards (Countable Income)
Licensed Boarding Home	
Eligible person	\$369.00
Eligible couple	\$738.00
Head of Household	
Living Alone	
Eligible person	\$261.00
Eligible couple	\$369.00
Eligible individual with ineligible spouse only	\$369.00
Living with Others	
Eligible person	\$241.00
Eligible couple	\$362.00
Living in Household of Another (Receiving Support and Maintenance)	
Eligible person	\$184.00
Eligible couple	\$312.00
Title XIX Approved Facility - includes person in acute care hospital, skilled nursing facility, intermediate care facility (Level A, B, and ICFMR), licensed special hospital (Class A, B, C) and Title XIX psychiatric hospital (for persons under 21 and 65 and over) or a combination of these facilities for a full calendar month.	\$714.00*

*The Medicaid "Cap" is applied to gross income
(i.e., income prior to application of income exclusions).



ANN KLEIN
COMMISSIONER

STATE OF NEW JERSEY
DEPARTMENT OF HUMAN SERVICES
TRENTON, N.J. 08623

NEW JERSEY DEPARTMENT OF HUMAN SERVICES

SUMMARY OF TESTIMONY DELIVERED BY DEPUTY COMMISSIONER GERALD REILLY
BEFORE THE SENATE COMMITTEE ON FINANCE SUBCOMMITTEE ON HEALTH
CONCERNING MEDICAID HOME HEALTH BENEFITS

May 22, 1979

Our Department would like to facilitate greater use of home health services by Medicaid recipients, particularly in situations where such services are a less costly alternative to institutional care. A shift in policy at the Federal level is crucial to our efforts. To overcome Medicaid's unintended bias against home care and toward institutional care, we propose the following:

1. Title XIX should be amended to, in certain situations, equalize institutional and community eligibility standards so that persons who might otherwise be institutionalized can remain in their own homes when it is cost effective to do so.

Under current Medicaid regulations, persons having up to \$568 in monthly income may receive Medicaid nursing home care, but may not receive Medicaid home health services unless their income is below the SSI standard. We propose that, for persons medically determined to require institutional care, Medicaid eligibility for home health services should be made equivalent to the institutional eligibility ceiling of \$568 per month. Once determined eligible, the person would pay a certain percent of his income toward the cost of his home health services.

2. Federal financial participation in the full range of home care services for low income persons should be provided through a single funding source such as Medicaid.

The medical orientation of Title XIX home health services precludes maintenance of the individual in the community without supplementary social and personal services derived from other sources. If one of these support services is disrupted, the home care recipient is often forced to enter an institution. Single source funding of a full range of home health related services will overcome the current fragmentation, and in many cases, may prevent or delay the use of more expensive institutional care.

MR. CHAIRMAN, DISTINGUISHED MEMBERS OF THE SUBCOMMITTEE:

I am Gerald Reilly, Deputy Commissioner of the New Jersey Department of Human Services, and former Director of the Department's Division of Medical Assistance and Health Services.

Faced with the increased costs of institutional care, with a severe shortage of long term care beds in our State, and with the knowledge that some of our recipients could be better served in the community, we are studying ways to increase the effective utilization of home health services in our Medicaid Program. A shift in policy at the Federal level is crucial to our efforts. Today I will summarize for you two proposals which constitute a practical approach to the expansion of Medicaid home health services, and which would broaden alternatives to institutionalization within a cost containment framework.

The following statistics about New Jersey's Medicaid Program clearly indicate why our interest in home health services has risen. Medicaid expenditures for nursing home care in our State were \$157.2 million in FY 78 and provided care for 18,730 persons. In addition, about 2,600 Medicaid eligible individuals are also awaiting placement into long term care facilities. At the same time, Medicaid's FY 78 home health expenditures were only \$3.8 million or less than one percent of the total for medical assistance. (However, this figure does represent a 99% increase over FY 77 home health expenditures). While the Federal and State Governments are paying a high price for nursing home care in New Jersey, a study conducted for our Department two years ago

showed that about 10% of the total nursing home population (about 1,800 persons), while meeting the medical necessity criteria for nursing home care, could have received appropriate care in the community, if the adequate social and medical services were available.

Increased availability of home health services under both Medicare and Medicaid would enable New Jersey and other states to create a more rational system of long term care, with levels of care more closely matched to individuals' needs. I would like to suggest two changes in the Medicaid Program that would foster greater utilization of home health care, and that would better integrate such services into a continuum of care.

First, Title XIX should be amended to, in certain situations, equalize institutional and community eligibility standards so that persons who might otherwise be institutionalized can remain in their own homes when it is cost effective to do so.

Under current Medicaid regulations, states may expand eligibility to persons needing nursing home care if their income is 300% of the SSI standard or less, that is, up to \$568 per month. However, in order to be income eligible for Medicaid home health services, these persons' incomes must fall below the state's SSI standard, which in New Jersey is \$227 per month. About 30 percent of New Jersey's elderly population fall into this "eligibility gap": their monthly incomes of between \$227 and \$568 make them potentially eligible for nursing home care but not for community based care.

Even the establishment of a medically needy program, which New Jersey currently does not have, would not be enough to resolve this problem. The income level to which a medically needy person must "spend down" is 133% of the AFDC standard for a unit of one; in New Jersey this would equal \$165 in monthly income. Evidence from other states has shown that this "spend down" income standard is so low that persons must have crushing health costs in order to become eligible for Medicaid. Rather than suffer a sharp drop to a subsistence level standard of living, they may choose to enter a nursing home, where they are at least guaranteed adequate food and shelter.

To equalize the institutional/community eligibility standards and to remove Medicaid's unintended bias toward institutionalization, we propose the following:

For persons medically determined to require institutional care, Medicaid eligibility for home health services (or medical day care) should be made equivalent to the institutional eligibility ceiling of \$568 per month. Once determined eligible, the person would pay a certain percent of his income toward the cost of his home health services. Persons should be permitted to choose the community care over the institutional option as long as the cost of community care is less than the net cost of institutional care. This provision would prevent utilization of home health services in situations where nursing home care would be more efficient. A reasonable argument could be made that, consistent with a social policy calling

for maximum independence, we should be willing to pay for such home based care even if it exceeds the cost of institutional care by some acceptable amount (for example, no more than 125%). However, this would compromise the cost containment aspect of our proposal.

In contrast to a spend-down program, this proposal would be simpler to administer, and with an income based co-pay system, it would better provide for an individual's normal costs of living while he is receiving home health services.

Our second proposal is that Federal financial participation in the full range of home care services for low income persons should be provided through a single funding source, such as Medicaid.

A frequently cited barrier to utilization of home health services as an alternative to institutionalization is fragmentation of funding sources and providers. The medical orientation of Title XIX home health services precludes maintenance of the individual in the community without supplementary social and personal services derived from other sources. Fragmentation of funding tends to foster fragmentation at the point of service delivery. For example, a typical Title XIX home health recipient might receive medical services from a home health agency, homemaker services from a Title XX contractor, and nutritional services through a Meals-on-Wheels program. If any of these services is disrupted, the entire plan of home treatment is often jeopardized.

In instances where home care is equally or less expensive than institutional care, the reluctance to expand Medicaid reimbursement to nonmedical services necessary for the implementation of the medical treatment plan is shortsighted. In the institutional setting, items such as housekeeping, meals, and personal care are part of the per diem cost that is Medicaid reimbursed. If parity between home care and institutional care is to be created, such services must be reimbursed when the recipient is not able to pay for or provide them himself.

As for the current fragmentation of service providers, a single source of reimbursement could encourage existing home health agencies to provide a more comprehensive package of services or to coordinate other providers and ensure that all necessary services are supplied.

We believe that increased utilization of home health services under Medicaid is dependent upon the availability of a full range of support services. If such reimbursement is not made available on an income related basis to individuals in their own homes, the result is often more expensive institutional care at a higher public cost.

SUMMARY

The two proposals that we have outlined here are expanded Medicaid eligibility for community care of persons otherwise needing institutionalization, and reimbursement for a broader range of

services under one funding stream. These proposals comprise a logical expansion of the existing Medicaid Program. The current system encourages institutional care even when less expensive home care is a viable option. Our two recommendations are designed to overcome this perverse incentive and to foster a more rational system of long term care.

Over the long run, increased home health services for all elderly and disabled persons through Medicare is a desirable national goal. However, we recognize that there are many unanswered questions - particularly in regard to cost - that currently prohibit such a large scale change in the Medicare program. Therefore, as an intermediate step, we are advocating the expansion of home health services to persons otherwise requiring Medicaid institutional care and in situations where the cost of home care is roughly equivalent to or cheaper than institutional care. Increased home health services in this context will alter Medicaid's current bias toward institutionalization, and at the same time, will provide further data that may help us effectively plan for the provision of such services on a universal basis.

The CHAIRMAN. Is that another way of saying we want to make every opportunity available for people to not have to go to institutional care?

Mr. RUSSO. Most definitely. We need institutional care. There is no question about it. But we need, probably more at this time, more of the other alternatives in the community.

There was some testimony given earlier by, I believe, Dr. Fox in reference to the nursing homes and the number of persons in nursing homes who might not have to be there. We know in New Jersey that there are people in nursing homes who don't have to be there.

We had an independent study made, and we found that people are in nursing homes who probably should not be there, who should be living in the community. The problem is that support services are not available in the community, so they are in a nursing home.

And when you get a gray area of a person, you are going to err to benefit that person. If he can be cared for in a nursing home and there is no other alternative, that individual will stay in the nursing home.

The CHAIRMAN. Don't we have some people in hospitals where it is not really necessary for them to be in a hospital except that there is a trigger for some of the provisions under medicare?

Mr. RUSSO. I don't really think there are people in hospitals.

The CHAIRMAN. I thought there were admissions that were for that purpose, to start the medicare clock running after discharge from the hospital.

Mr. RUSSO. There are people in hospitals because of the 3-day hospital limitation under the medicare program, but my understanding is that the reconciliation bill before the Congress has a clause in there to eliminate that.

I don't know whether that is still in there or what the status of it is, but at one time it was in there. Other than the 3-day medicare provision, there are a lot of people in hospitals that require long-term care, not because they have been placed there specifically to provide long-term care but because the alternates to get them out of the hospital were not available.

There are not direct admissions for long-term care purposes.

Dr. VLADECK. If I may pursue that one more moment, Senator, we, as Tom knows, had quite a bit of controversy in this over the last several years in terms of the reimbursement to hospitals for patients awaiting nursing home placement.

As we have begun to try to resolve that and thought that was one problem solved, we have begun to regularly hear from the hospitals about the patients who no longer belong in the hospitals who have been told so; certified by PSRO's as no longer needing acute care, who the PSRO's had not certified for skilled or intermediate care but who can't be sent home without some combination of home health services.

And those people are in the hospitals, particularly in urban areas in considerable numbers.

Mr. RUSSO. One of the biggest problems that we face, and this has been discussed earlier in the other testimony, is the eligibility issue.

The CHAIRMAN. Did you have a statement for our record, by the way?

Mr. RUSSO. Yes; I do.

The CHAIRMAN. We will include that.

Mr. RUSSO. The eligibility issue, for those States that do not have a medical need program, they charge to H.R. 6194, the Medicaid Community Care Act of 1980, attempting to address that issue.

But it is a burning issue. We are talking about alternate care and we are talking about expanding home health care, and medical day care, and all of the other services that are available in the community under the current definitions of the medicaid program.

The biggest barrier is the eligibility standard and we have to address that issue. If we don't address that issue we are going to have people living in the community who are not going to get services under the medicaid program. There is no question about it.

We have got to close the gap between the community eligibility cap and the institutional eligibility cap, and if we don't do that we are still going to continue to drive people to institutions because we are going to pay for them in the institutions.

But they are living at home and their income is below a certain standard and there is a large discrepancy of nearly \$500 between institutional and the community cap. We are not going to be able to provide these services.

The CHAIRMAN. This is one of the things that you feel should be addressed now?

Mr. RUSSO. This should be addressed as soon as we can address it.

The CHAIRMAN. The program that we would legislate through the bill, S. 2809 is to be demonstrated over a period of 3 years. In other words, experience of 3 years before a final national program is designed.

The things you suggest seem to be those that could be met within the demonstration period.

Mr. Russo. This should be addressed at the present time because as of today an individual making—I am talking about an individual, not a family situation—who has an income of less than \$714 can receive care in the nursing home and medicaid will pay the full cost of that care.

However, that same individual, if he were living in the community and his income exceeded \$261, would not be eligible for medicaid services. We are pushing people, basically, into nursing homes for care.

The CHAIRMAN. You know, the PATS, the preadmission screening and assessment teams, under the bill, we created them for the purpose of screening, assessing and establishing a plan of care prior to any person receiving benefits under title XXI.

They would be designated by each State and may be any one of the following entities: local, city or county health departments. What you are suggesting, Freeholder Sigmund, is a possibility, or you suggested a mandate specifically for county governments?

Freeholder SIGMUND. Senator, I never presume to dictate a mandate of that magnitude. I am suggesting that the experience countrywide right now seems to reflect that of New Jersey, and that is, willy-nilly, because the county government in the United

States is the only regional government de facto in the United States.

People talk regionalism, eat it and sleep it, and all the rest of it. But the only de facto regional government that exists in the United States is the county government.

Because of a series of factors, and because the welfare system is run out of the counties and all sorts of other factors, the county becomes the focus of a lot of these problems.

I was just suggesting that if you were talking about some sort of coordinating mechanism, that you do not create another Federal bureaucracy, that you use this already—existing regional government that already has a lot of these problems falling on its shoulders as the ongoing organizing mechanism throughout the country perhaps with the State Department of Health overlooking it, or whatever.

I came today to tell you about what we find in Mercer County, and I know that we find in the counties across the State in our extension discussions I have had with NACO personnel, et cetera, across the country and a lot of the solutions are those that have already been obviously suggested earlier today both at this panel and earlier on for alternatives, et cetera, that could be implemented right now.

But I know that in our county we are ready and willing to implement right now but that we have the problem both of eligibility criteria and of funding to face rather than that of organization to face. We are ready and willing to be able to organize the solutions. We don't have the funding and we have the problem about eligibility.

The CHAIRMAN. Tell us about Mercer County and how you do bring together, in an orderly way, a response to the services. Do people have to shop around Mercer or is there a central place for people to tie in and know what services are available?

Freeholder SIGMUND. There is not, as yet, a central place. We run the nursing home that is effectively the only medicaid facility in the county because, as you know, private nursing homes are reluctant at best and recalcitrant at worst about accepting medicaid patients.

So, in effect, we run the medicaid facility in the county. The problem that was just described about the hospitals in the county running to us and saying, "Look, we have all these people here who shouldn't be here. You take them at Donnelly Hospital." It happens every day. We can't do it. We can't absorb them.

So, what do you do? You either expand the Donnelly Hospitals of this country—that is, the county nursing homes of this country—that are, in effect, the only medicaid facilities ad infinitum, or you go to some sort of intermediate solutions.

We have in the county a human services department that would be able to act as a coordinator. We, of course, have the county welfare department, as every county in the United States does, that can act as a piece of that puzzle.

It can be done on the county level. And the problems come from the county. They come from the municipalities. There are several wonderful people out here right now from Mercer County who, for instance, are very much involved in the various social service

delivery systems, particularly those that have to do with caring for the infirm elderly, the less infirm elderly and they tend to come to the county for extra funding for those programs.

As I say, it is becoming more and more the focal point for all these levels of government, all the levels of the private social service agencies, the hospitals themselves to turn to in order to try to resolve and to coordinate these problems.

I am just arguing that that is probably a good idea. We had, for instance, a request that we are still trying to work out. Here is one of the alternatives that we are trying to get going and that is to fund, through the county, some \$62,000 worth of contribution toward this congregate or assisted living concept.

With the \$62,000 that we would have to spend as part of the pot for the congregate living, we could take care of only four people a year at Donnelly Hospital on the county taxpayer's dollar. We can take care of 40 people a year in the congregate or assisted living situation on the county taxpayer's dollar.

It is that kind of a solution that we are eager and willing to work on.

Family day care centers. We have a proposal from a group in the county that would like to run family day care centers for senior citizens, as some people do on a licensed basis for children. We don't have enough funding under any of the Older Americans Act titles to really fund that on a proper basis.

But, of course, there is another solution that is an intermediate solution. Sending people and more money to the existing day care centers or resource centers in senior citizen projects. I know one person in the audience right here today who does that. She has a terrible time having that program survive.

That is the kind of thing that if it does survive and if it does flourish, keeps people in a senior citizen project for much longer than they would be able to ordinarily. It is those kinds of solutions that I think county governments can deal with very effectively.

The CHAIRMAN. And, of course, those specifics are included within the Senate bill that we have been addressing.

Freeholder SIGMUND. I know what the alternatives are. All I am suggesting is the organizing mechanism.

The CHAIRMAN. That congregate response, that is the most dramatic—\$62,000, and that would be—

Freeholder SIGMUND. Because you can mix it in with HUD funds and section 8 funds under the U.S. Housing Act and all sorts of other things. \$62,000 is what it would take to take care of four people at Donnelly Hospital in a year. Again, that is \$62,000 of county taxpayer money. That is not all the third party reimbursement money that we get for those same four people at Donnelly. In other words, it costs more than that to take care of those people at Donnelly.

But, of the county property taxpayer dollar that has to go into that mix, \$62,000 that we spend at the congregate living facility takes care of 40 people as opposed to four people at Donnelly.

The CHAIRMAN. Congregate housing legislation is something I have worked on a long time to try to have this congregate response; some of the chores, some of the needs taken care of to keep people in a home setting.

In what community are you going to reach people with the congregate idea?

Freeholder SIGMUND. In Trenton right now.

The CHAIRMAN. In a public housing project?

Freeholder SIGMUND. Yes.

The CHAIRMAN. It is certainly the easiest. There you have the community.

Freeholder SIGMUND. This is actually run through the Lutheran Church, but it is on a nonprofit basis. They are eligible for all the funding that a public housing project would be eligible for. I would suggest that you do expand the category, eligible under existing programs, to include nonprofit housing as well as regular public housing.

The CHAIRMAN. And even beyond, as a matter of fact.

Freeholder SIGMUND. You used to call it apartment hotels, and it was fancy.

The CHAIRMAN. That is a section 202 project?

Dr. VLADECK. Yes, it is.

If I could just say something about the 202 congregate housing experience, that is one of the cases where we seem to have a public program that nobody can argue with because it works so well.

The only concern I would have is, given construction costs these days and budget problems these days, the question of getting similar services into existing dwellings, regardless of ownership. There have been experiments in New York State and other States with what they call enriched housing, which is simply renting or purchasing a block of existing apartments and then providing the same kinds of services as you do in new 202 with congregate housing developments and a section 8 subsidy.

The problem, of course, is that the Federal subsidies at the moment tend to be limited to federally supported housing and I would very strongly urge consideration of expansion of Older Americans Act or other support for congregate services, not only 202 projects but existing nonpublic housing as well.

The CHAIRMAN. I agree with you completely, but you know the problems we had this year starting the year with no budget request for congregate housing and then having to battle for \$10 million for the whole country, and getting it into the appropriations. But I agree with you.

Freeholder SIGMUND. If our statistics are right, just think of the multiplication out of that \$10 million, if you are doing it versus a nursing home expansion.

The CHAIRMAN. Exactly.

Yes, Mr. Russo.

Mr. Russo. Senator, if I may, I would like to address the 12 long-term care channeling projects that have been approved by the Health Care Financing Administration to review the study methods of improving community health care.

I would like to address this because they are demonstration projects. I think we should consider some of the problems that we have had in the past with demonstration projects. We have hundreds of demonstration projects in this country funded by the various sources.

They exist for 2, 3, 4 years, whatever the duration of the project is. Many of them prove to be very successful, very effective, cost effective, good from the program standpoint, but then, when the demonstration expires two things happen: The funding source expires and no one has the funds to pick up the project and continue with it, so they die; the other problem is that most of the demonstration projects are given under some sort of a waiver provision and that once the demonstration ends, that waiver also terminates and then you go back to your old rules in the game and the old rules of the game don't permit you to carry on the project even if you have the funding to do so.

So I think that is something that very seriously has to be looked at. I think there is not much sense in providing moneys and initiatives for demonstration if the outlook for continuing them when they prove good, successful, and cost effective doesn't really exist.

And I am fearful that the same thing may happen with these 12 long-term care channeling projects.

Dr. VLADECK. If I may say one thing further about both the channeling projects and the proposal in your bill, S. 2809. In my own view, and I realize it is not entirely shared, there is no great mystery. There is no great magic involved in establishing something like the PAT agencies described in your bill.

There is a lot of unease because we haven't done it before and, therefore, in the current climate, let's do it on a demonstration basis rather than enacting a statute. But every statute, in a sense—particularly these days—is in a sense a demonstration. Congress can always undo what it has done.

I think a lot of people who are in the business of providing services are a little battle scarred by the history of federally supported demonstrations. And if people think something is a good idea we ought to go do it and if it turns out not to be a good idea we can undo it.

I would share very strongly Mr. Russo's sense that to the extent that we call things demonstrations because we are afraid they don't work, they might not work, the cost of calling it a demonstration may be greater than the advantages. If it doesn't work and it is not a demonstration you can still stop doing it.

I feel that way about the channeling projects and I feel that way about—although I don't agree with everything in S. 2809, with the basic thrust of it. If it makes sense to do this, let's do it and let's do it in a number of places.

The CHAIRMAN. Does S. 2809 to you mean no diminution of Federal money support but a reorganization of the delivery mechanism? I would think that there is no question that if this is successful—we had some testimony before you were here that if we succeed with this approach it will not mean a net reduction of Federal expenditures and the reason is, more people will be served, which is fine, but in a different way.

Freeholder SIGMUND. But more people will be served.

The CHAIRMAN. And remaining home, the less expensive way, so we will be meeting more human needs.

Dr. VLADECK. Senator, public expenditures for nursing home care have been growing at a compounded annual rate of 15 to 18 per-

cent for the last number of years and everyone projects they will continue to grow at least as fast.

We are going to be spending more money on the care of the frail elderly one way or the other. If we are going to be spending more money let's spend it better.

The CHAIRMAN. That is the point, absolutely. And reaching more. I think it is implicit, but you better say that.

Dr. VLADECK. I will be happy to say that as well—spending it better for more people.

Freeholder SIGMUND. To pick up on this particular point, of course the demonstration project mentality is the thing that does do in a lot of good programs and I think, unfortunately, it has been responsible for a lot of the attitudes that we have in the United States that these social programs don't work; why do we keep spending money on them?

The problem is that ironically the ones that do work are the ones that go out of business. We have demonstrated they work and then they don't get funded anymore. This kind of an approach to a program that takes care of the infirm elderly, something that all of us are going to have to face either in our own lives or in the lives of our family members at one point or another, is probably the best place to start changing that demonstration mentality because people are more willing to spend money on a long-term permanent basis on this particular social problem than almost any other because it hits us all, as long as the criteria are not too limited.

I think another mistake that we have made in this country on a continuing basis is to assume that the only people who should be helped by social programs are those who are at a low economic level. I think that that has also created enormous resentment about social programs in the United States.

It is either all or nothing. Once you reach the cutoff level you are literally cut off from those services. Again, if we could build into all of these kinds of services for the infirm elderly a sliding scale approach, one that says families that can help should help, but we are not going to cut them off at the point at which they make x number of dollars; we are going to continue to help them.

All of this will add not only immeasurably to the solution of this problem but will help the American public to understand what it is that government at all levels are trying to do about taking care of social needs.

I would like to, if I might, tell one story that has to do with what I have discovered as gaps in the present system that I think can be addressed more simply than a whole new approach. And this doesn't have to do with the care of the infirm elderly but simply the whole question of home health care.

In late 1978, the very young—at that time 19- or 20-year-old daughter of two of our county employees in Mercer County contracted a very, very rare viral neurological disease. It turned out to be terminal and absolutely past any remedy. They could do nothing for it at any stage of the disease. You simply have to watch the person deteriorate and die.

After 3 months of being in the hospital the team met—whatever those initials are—took over and they told the parents since it is a terminal illness and they needed the bed she had to go home. So

they took her home and they paid for nursing care at home with what was left of their major medical policy after paying off all the hospital bills.

And, of course, that money soon became depleted. At that point, because both of the parents had been long-term county employees, another county employee came to me and told me about this plight.

I then told the father about the SSI program and the fact that she would be eligible, because she was permanently and totally disabled, for SSI benefits and that that would trigger some sort of medicaid help, whatever was available for medicaid help for home health care.

The amazing thing about this part of the story is that nobody at the hospital at the time of the discharge of that girl had told the parents about that. It was pure happenstance that they ever found out that she was eligible for medicaid at all through the SSI mechanism.

There is a gap in the system obviously that needs to be filled and could be filled immediately. You don't need any new legislation to have people in hospitals tell people what their rights are, and what they should be looking at that already exists out in the system.

Then, they found out because the child was so young, that she could only get \$164 a month from the SSI benefits but, of course, it did trigger the medicaid mechanism.

What they have been able to get from medicaid though is something that puts them and, I imagine, everybody else into a Catch-22 situation, and probably some of this has already been discussed, but let me tell it from the point of view of these people.

They are allowed aides. They are not allowed skilled nurses to come into the home under medicaid. The aides are allowed to bathe the girl, to turn her over and to straighten the room, but in this case they can't even feed her because feeding is accomplished through a nasal gastric tube and these aides are not allowed to use that tube, nor can they touch the catheter or the suction machine that is needed to keep her clear enough to breathe.

Therefore, the mother kept trying to work, would have to return home to keep performing these functions that the aides were not allowed to perform because medicaid will not pay for a licensed practical nurse or an RN to come and provide home health care.

It kept getting more and more complicated. For a while the mother quit her job. Then, of course, the economic situation got worse because she wasn't working. Then she went back to work and she is caught in the syndrome again of having to return every couple of hours in order to suction out the child or to feed her, all these functions that simply are not allowed under the medicaid program, again, something that could be just expanded now.

So the other big problem that this family finds is that doctors are not allowed to come under medicaid home health, to the home but you can get an ambulance, put the patient in the ambulance, take the patient in the ambulance to the doctor and medicaid will pay the fee for the ambulance and the doctor, but you can't do it the other way around. You can't have the doctor come to the patient.

And, of course, in a situation like that, that is practically an impossibility plus about three times more expensive than if the doctor would come to the house. Those are a few of the kinds of

gaps that could be covered right now, allowing LPN's or some sort of skilled nursing or better trained aides, who would be allowed to perform these functions to be covered by medicaid allowing some sort of sliding scale perhaps or RN care itself because, of course, these people even now have to pay for somebody to take care of the child from 11 o'clock at night until the morning time so that they can get some sleep to be able to go to work the next day.

And it should allow for the doctors to visit at the home as well as taking them out of the home. Those are some of the suggestions that I would have to correct the system right now.

The CHAIRMAN. Did I ask about training people for the comprehensive response within the home and home health care and these ancillary chores really?

Freeholder SIGMUND. Right.

The CHAIRMAN. Are there people? Is this an occupation that has any attraction or is it possible to find people to do these home health care jobs?

Mr. RUSSO. Yes.

The CHAIRMAN. In going the next step, and I know it would be very difficult to go to the simple health procedures that are barred now that you just described.

Freeholder SIGMUND. If the mother can be trained and the father can be trained to do it why can't the home health aides be trained to do it?

Mr. Russo. I think, if I may, Senator, the description or example, without getting into the technical accuracies of the statements on medicaid eligibility, simply points out the issue discussed earlier, and that is the fragmentation and the definitions of when medical care is medical care and social care is social care and this real gray area that we get into.

And I think it was highlighted by Barbara's example, although I am not sure of the technical accuracy of what medicaid will cover and will not cover. I don't think it is necessary to go into that at all, but I think it highlights the issue before us and that is the fragmentation of the services.

And once you reach a certain definition medical care falls off and you pick up social care or personal care and one can't do the other, and that is the whole thrust of getting one funding source and one administrative source to take care of some of these areas.

Freeholder SIGMUND. Senator, by the way, this family did offer their home to any member of the staff who would like to come and see this particular situation as an example of what families do go through and the kind of help that they think they would need.

The CHAIRMAN. I understand that this is not federally hard and fast in some of these areas. States can come in and have some ability under the law to make commonsense adjustments here. Is that what you are telling me, Mr. Russo? Do you understand your State authority to be such that some of these road blocks can be removed at the State level?

Dr. VLADECK. Tom may want to respond to that. Basically, yes, although it is only partially within the State's legal jurisdiction. There is no question under title XX, or even under medicaid, you can cover a broader range of services and you can define what you pay for.

But, to ask us to get into the issues of the appropriate professional accreditation for a mix of services that may come under the coverage of a Nurse Practice Act, or so forth, is perhaps something that State governments should have the courage to approach more systematically but is fraught with perils of one kind or another.

The CHAIRMAN. This would have to—and maybe we are getting, not afield but perhaps within our time limitations too far afield—be some professional training that could bridge this whole range.

I wonder if in Mercer Community College anybody is structuring something that could be acceptable within the professional community. Why couldn't there be this extension of the nurse's aide idea?

Freeholder SIGMUND. If anybody out there who is muttering knows anything differently so that I could help this couple, please tell me, but for 2 years they have been going through this and these are the regulations that have been enunciated to them by every authority in the State of New Jersey.

The CHAIRMAN. Now we are decreasing our need for school teachers, but it seems to me we are increasing our need for service people. It should be, I would think, promising for those who like to feel themselves of importance to others to get into some of these activities, and I would think the community colleges would be a good place to have this as a part of their curriculum.

Now, what have we missed here? We are well beyond the time that I promised everybody we would have here this afternoon. Can we go down the line with conclusions?

Mr. Russo. I would like to make a suggestion that in reference to an earlier statement I made of the need for some national policy or guidelines and not simply various caps from time to time to fill gaps and provide the services and still fragment the system, that some possibility be given to a kind of White House conference on health or home health care.

We have a White House Conference on Aging. We have one in the area of youth. To my knowledge, we have not had anything in this area of home health care, or the health area and possibly it might be beneficial if something of that type might be considered.

The CHAIRMAN. That might be something worthy of tomorrow's gathering here, too. Are you going to be here tomorrow?

Mr. Russo. I will be here tomorrow.

The CHAIRMAN. Good.

Dr. VLADECK. Senator, in conversations I have had with congressional staff people and health and human services people relative to your bill, to the Waxman-Pepper bill, to others, the constant response we get is that we are in a time of increasing perceived budgetary problems and everyone is very reluctant to take a budgetary risk; that maybe if we expand eligibility for home health services instead of substituting for nursing home services it might cost us an extra billion dollars a year or \$2 billion dollars a year that we don't have.

I would suggest, and I have made the argument and would like it to be on the record of today's proceedings, that if we do nothing we are taking an enormous risk. In fact, if we do nothing instead 1½ million people in nursing homes at \$15,000 a year now, by the end of the century we are going to have 2½ million people in nursing homes.

We are still going to have waiting lists. We are still going to have people inadequately served. We are going to be spending three times or four times as much. There already are entitlements for institutional services, and they are going to eat up all our dollars unless we start to channel people away from them toward services that they would rather have.

If that means in the short term some budgetary risk, I think it is a risk well worth making because Federal nursing home expenditures are now growing at the rate on the order of \$1 billion a year.

That is just going to compound forever into the future unless we start to turn things around.

Freeholder SIGMUND. A White House conference was suggested by Mr. Russo. I would be happy to offer a courthouse conference and get together with some more of the county officials, at least in this State, and discuss your bill and come back with recommendations from the county.

I do want to say that I saw something on television last night that there are going to be something like 50 million strong people 55 or over within the next 10 years, so I think that we don't have to worry about political support for these programs.

The CHAIRMAN. Excellent. We would like to have the opportunity to send you some written questions, as Senator Bradley mentioned earlier, and I think we might, too.

Finally, are there any statements from those who were here today and as part of this hearing you want to include in our record that have not been included?

Ms. WINIFRED LIVENGOOD. I just want to say thank you very much, Senator, for convening this very wonderful and first historic hearing in New Jersey on home health legislation. We really appreciate, from the industry and, most of all, from the patients who we serve who are currently not really getting a fair deal. So, we thank you very much for coming. [Applause.]

The CHAIRMAN. We thank you for all you have done through the year to develop the full program, and this has been so helpful to us. Thank you.

Ms. WINIFRED LIVENGOOD. You have helped us out in leading the Congress down there. It wouldn't have gotten as far as it has, and we thank you.

The CHAIRMAN. Thank you all.

At this point I order printed all statements of those who could not attend and other pertinent material submitted for the record including the text of health care conference to be held tomorrow.

[The material referred to follows:]



ASSOCIATION FOR RETARDED CITIZENS • NEW JERSEY

99 Bayard Street, New Brunswick, N.J. 08901

201/246-2525

Emery Stokes
PresidentJohn P. Scagnelli
Executive Director

December 5, 1980

Ms. Letitia Chambers
U. S. Senate Committee on Human Resources
Senate Office Building
Washington, D. C. 20201

Dear Ms. Chambers:

It was good to chat with you at ETS on the 24th. We appreciated the real involvement of the various Congressional staff members.

Pursuant to our conversation, I am enclosing a statement on behalf of ARC/NJ for inclusion in the record of the hearings of November 23-24.

Thank you for this accommodation.

Sincerely,

Elizabeth M. Boggs, Ph.D.
Chairman,
Committee on Governmental Affairs

EMG:mb
enc.



Emery Stokes
President

ASSOCIATION FOR RETARDED CITIZENS • NEW JERSEY

99 Bayard Street. New Brunswick, N.J. 08901

201/246-2525

John P. Scagnelli
Executive Director

STATEMENT PREPARED FOR
HEARING ON COMMUNITY AND HOME CARE

U. S. Senate Committees on Human Resources and Aging
Senators Harrison Williams and Bill Bradley presiding

Center for Health Affairs
Princeton, New Jersey
Sunday, November 23, 1980

"Noninstitutional Long Term Care Services
for the Elderly and Disabled Act".
(S. 2809 96th Congress 2nd Session)

We of the Association for Retarded Citizens in New Jersey join with others in taking pride in the active role being played by both our U. S. Senators in furthering legislation to assist citizens of any age who may have physical or mental impairments to remain in their homes and communities. We welcome the forward thrust represented by S. 2809, sponsored by both Senators Williams and Bradley. We affirm our conviction that current efforts in this state and elsewhere to provide community based living arrangements and services for persons formerly residing in state institutions or nursing homes must have a stable funding base and must result in a credible, reliable, system of supports for vulnerable persons in the community lest persons deinstitutionalized find themselves in conditions more deplorable than those they were experiencing in the secure if sometimes barren environments of the larger and more segregated facilities.

It is our understanding that it is the intent of the bill to provide for all types of persons who qualify as disabled under the Social Security Act and who have been institutionalized or who might be at risk of institutionalization. This means adults of working age as well as older persons, and even includes children with comparable disabilities. The needs of such persons will vary with current age, with age at onset, and with the type and degree of specific functional impairments.

There are approximately 300,000 persons with identifiable mental retardation receiving SSI benefits, and about 250,000 receiving adult disabled child's benefits

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under Title II. Allowing for dual benefits these two programs account for at least 400,000 persons of whom perhaps 100,000 are in some type of institution.

The Social Security definition of disability implies a degree of severity of the disabling condition such that it can be safely said that almost any eligible person whose primary disability is mental retardation must be considered at risk of admission to an institution if he or she were to be left without economic and social supports.

The two income maintenance programs within the Social Security Act (Title XVI and Title II) do supply basic income to cover food and lodging under favorable circumstances for persons that have no other income. Their complementary health care payment components (Titles XIX and XVIII) do not adequately cover health care needs of those with chronic disabling conditions, however. Moreover, as a number of demonstration projects have already shown, many of the needs experienced by such persons are not medical but social and instrumental. Many of these latter needs can be met in principle under Title XX but, with the "capping" of appropriations under that Title, the availability of chore serviced, housekeeping assistance, home maintenance, shopping, transportation and the like for senior citizens and the non-elderly disabled are, de facto, very limited.

Furthermore, where disability includes a mental impairment, there can arise a range of needs not adequately encompassed under the usual definitions of "home health" or "homemaker-home health aide". There remains a need for psychosocial counseling, guidance, advocacy, case management, social supervision, and, on occasion, protective intervention which are not adequately delineated or apparently contemplated under the text of S. 2809 as introduced.

Such needs are not limited to the mentally retarded. Indeed recent surveys indicate that in nursing homes most of which cater to the elderly at least two

(cont'd)

thirds of the patients have significant mental impairments, mostly of a benevolent kind. Like the majority of severely retarded persons, they do not represent a threat to the well being of others, but are at risk of harm to themselves as a result of their own lack of capacity to protect themselves and their own interest.

We are also concerned that S. 2809 will not permit benefits to flow to disabled persons whose income slightly exceeds the limits for SSI, but who lack eligibility for a higher social security benefit. In New Jersey, where there is no medical indigency component to medicaid, this would impose a particular hardship on disabled persons with incomes in the range of \$250 to \$700 per month. Such persons are not, under present rules, eligible for medicaid payments except to cover the total cost of board, maintenance, social services, personal care, personal needs and medical care to the extent that these costs exceed their available income. These same persons cannot, however, put together a less costly package of home or community based care where the combined costs exceed their actual income.

We note, furthermore, that S. 2809 contemplates co-payments from persons who are receiving SSI or have equivalent income. Since the SSI level is calculated to provide only a minimally adequate level of subsistence without significant budgeting for the services of others, it seems inappropriate to insist on co-payments at these levels.

Finally, we have some real reservations about the structure of a Title XXI which depends on (a) depleting other Titles and (b) an authority to draw on general revenues but without any entitlement.

(cont'd)

In Summary

1. We applaud the stated purposes of the bill.
2. We believe the provisions are inadequate to achieve the purposes and hence to meet the expectations stated:
 - (a) The covered services do not include sufficient attention to social and instrumental needs, including supervision for persons with impaired social competence.

We recommend coverage for social and instrumental services including psychosocial counseling, social supervision and protective services.
 - (b) The bill discriminates against disabled persons with low incomes (above SSI level) who, for one reason or another, do not currently qualify for Title II benefits.
 - (c) For persons in the income range of \$250 to \$700 a month the bill fails to provide equal access to comparable services for persons in community situations as compared to persons in medicaid certified institutions for the retarded or child psychiatric units.
3. We advocate eligibility for persons meeting the disability tests who may have income above SSI but below 3 x SSI.
4. We consider the co-payment requirement for persons at or below the SSI level (federal level of \$238 per month) unreasonable.
5. We have the grave reservations about massive mandatory rechanneling of funding currently delivered under Titles XIX and XX.

Submitted for the record in connection with the November 23, 1980, joint hearing of the Senate Committee on Labor and Human Resources and the Senate Special Committee on Aging held in Princeton, NJ

Submitted by Eileen C. Murray, Director, Medical Personnel Pool, of Saddlebrook, New Jersey

As we all know, the costs of hospital-based care have increased at a very rapid rate in recent years. Similarly, long-term care expenditures for those in nursing homes are on the rise, consuming more and more private and public dollars. These budgetary facts have led to a heightened interest in noninstitutional home care, such as home health care, which I know both Senator Bradley and Senator Williams share.

Because monies for providing home-based care are scarce, there is great concern in seeing the Medicare and Medicaid services delivered efficiently and at a reasonable cost. For that reason, I felt that you might be interested in looking carefully at a working solution. This is an alternative to the sometimes polarized positions taken by non-profit and proprietary agencies.

We are a proprietary agency, interested in achieving the best standards of service to the people entitled to Medicare assistance. We feel strongly that such legislation should not proceed from the assumption that the best interests of the patients and government are inimical to those of proprietary agencies. Indeed, as Director of Medical Personnel Pool for over ten years, I believe that private agencies can make the program more economical and efficient and thus provide a tremendous service to everyone involved when - and this is an important proviso - they work in conjunction with and under the auspices of non-profit home health care providers.

Let me illustrate this alternate point of view by briefly describing how the program works in the Bergen-Passaic area. The non-profit agencies in this area are responsible for evaluating each patient's needs and legal rights to Medicare benefits. In addition, they provide all counselling, check constantly the service being provided by the subcontracting proprietary agencies, provide all sophisticated care, i.e., visiting nurses, physio-therapists and confirm that the state requirements, such as weekly narratives, are carried out.

In instances where non-profit agencies give State Certification classes and assign these aides, we are a very necessary adjunct to their rosters. In the past, before proprietary agencies were used, there was a huge gap between those patients who qualified for Medicare and those fortunate enough to receive care. Today, if a patient involved needs Medicare assistance and is evaluated and approved, when the non-profit has no one to send it calls upon the proprietary and refers the case to it. All decisions regarding length, kind of coverage and evaluation of aides are made by the non-profit provider. The advantages of a system such as this are as follows:

1. Neither the non-profit agency nor the proprietary agency has vertical control. There is a dynamic tension which keeps everybody honest. The non-profit agency has total discretionary power; may deal (or not deal) with a proprietary agency as it sees fit. This creates a competition among the proprietary agencies and motivates them to keep efficiency and service at a high level and costs competitively reasonable.
2. All expenses involved in training aides including advertising, classroom space, manuals and equipment, faculty salaries, office salaries, continuing in-service programs and many others are assumed 100% by the proprietary agencies. This necessitates large volume in order to meet such investments and expenses and still make a fair profit. Since the non-profits operate like comparison shoppers, the rate charged is kept stable.
3. If a proprietary agency provides a Certified Home Health Aide, careful adherence to the rules and regulations set forth by the non-profit agency is a must. This includes confirmation of a time test and a physical examination. After the aide is placed, weekly narratives are submitted, signed by the Registered Nurse from the non-profit agency. Ineptitude, personality problems or insensitivity are not tolerated. Because most aides are in the nursing field for a relatively short period of time it is mandatory that they spend the first few months or so

under constant surveillance by the non-profit agency. As partners each must perform on a high level if they are to get along. Each, also in effect, polices the other. This may sound like strong language, but the real danger lies in the autonomy inherent in the systems being opted for by the non-profit agencies and those proprietaries seeking licensure.

4. Checks and balances are imperative if carelessness, loose supervision or price gouging are to be avoided. Such inclinations are implicitly inhibited by a system such as we feel we employ harmoniously in Bergen and Passaic Counties. At the risk of being repetitive, the non-profit agencies have the buying power and the rate is kept stable due to the competition among the private agencies.
5. The rate which Medical Personnel Pool of Saddle Brook, Inc., charges Medicare for home health care is exactly the same as the rate charged to a private patient. There is not one penny increase in rate simply because the government is paying the bill. By linking the Medicare rate and the private rate, the government is spared the possibility of excessive charges. (Such a guideline were it to be made law would provide a logical way of protecting the interests of both the government and the private health care agency.)

Now, I would like to address myself to the ~~_____~~ ~~_____~~ potential problems of fraud and abuse and excessive costs among proprietary home health providers. Obviously these same potential dangers exist within the non-profit community. The lack of recognition anywhere in your letter is disconcerting. In the many years prior to the use of supplemental health care help from proprietaries, the non-profit agencies were awarded grants and given many incentives to care for deserving patients under Medicare laws. Now, without grants or payment of any kind other than those hours an aide actually works, the job is being done and done well, with the help of proprietary agencies.

It would be very interesting to make a comparison study of the results of methods of several years ago and today's cohesive, partnership method, used in Bergen and Passaic Counties. I must point out that this is the result of the excellent work being done by non-profit agencies in a condition where they can pull from a labor force which was not available to them in the past.

In closing, let me commend the non-profit agencies in our area. Medical Personnel Pool of Saddle Brook feels privileged to work with honest and dedicated people such as those at Community Nursing Service in Hackensack, Nursing Service Incorporated in Ridgewood, Tri-Hospital in Passaic, Passaic Valley Visiting Service in Little Falls, Visiting Nurses of North Bergen in Mahwah, Englewood Public Health in Englewood and Protective Services for the Frail Elderly in Hackensack.

The people in these organizations work long the hard to provide the best care possible to those who so desperately need it. I am proud of what these agencies have achieved in the Bergen-Passaic area and equally proud to have helped. We feel this system is a healthy alternative to unilateral control by either profit or non-profit agencies.

A Statement of Policy of the Mercer County Board of Freeholders
With Regard to
The Needs of the Infirm Elderly

The Board of Freeholders of Mercer County recognizes the urgent need for compassionate care and adequate housing for the infirm elderly in our community. The elderly cannot wait for a more favorable economic climate or a better tax base; their need is now and it grows more acute every day. The most desperate situation is that faced by the infirm elderly from low and moderate income groups. Inflation has virtually destroyed their ability to fulfill basic needs for food, shelter and medical attention. We recognize also that these needs will be faced by increasingly large numbers of our population, as spiralling costs put health care out of the reach of more and more of our citizens.

No one group or governmental agency can address all the needs of the elderly. It is the intent, however, of the Mercer County Board of Freeholders to enunciate and, with the cooperation of this Administration, implement a broad-based policy to address the desperate needs of those elderly who are economically and physically unable to meet that need themselves. It was to this need that President Barbara Sigmund, in her recent inaugural speech, referred, as follows:

"This Freeholder Board knows that high on the people's agenda for the 1980's in this county are such items as the need for more Medicaid beds and alternative ways of caring for our infirm aged."

Re-building Donnelly Hospital

Our first concern is to improve the quality and availability of long-term health care for Medicaid-eligible elderly persons in Mercer County. Donnelly Hospital, a county-operated facility, provides overwhelmingly the largest number of Medicaid beds in Mercer County. There are currently 253 infirm, needy elderly on the waiting list for admission to Donnelly. Private, long-term care facilities have been able to serve only a small fraction of these elderly in need, because Medicaid reimbursement has not allowed for a

sufficient economic return.

Donnelly Hospital is a very old facility, originally designed to care for tubercular patients. Both physical structure and age make the present plant inadequate to provide long-term health care in a cost-efficient manner. It is impossible to meet federal and state requirements and ensure maximum Medicaid reimbursement, so that the expenditures of tax monies are kept at a minimum, unless Donnelly is rebuilt.

A Certificate of Need was secured from the State Department of Health in September, 1979, in order that a necessary long-range plan for Donnelly could be prepared. The plan is to include a review of the programmatic and financial feasibility of rebuilding the present facility, and expanding its capacity, together with a study of the uses to which the present building would be put. The consultant would also prepare the second Certificate of Need required by the state to actually commence re-building.

There can be no question that the continued operation of Donnelly Hospital is vital to the people of Mercer County. The Board of Freeholders and the Donnelly Hospital Board of Managers are strongly of the opinion, reinforced by experts at the state and federal level, that Donnelly must be rebuilt to meet present day standards of staffing and operation and to provide the desirable level of patient care.

We, therefore, call upon the Administration to proceed without delay to engage a consultant to prepare the study which will enable us to carry out our expressed intent to rebuild Donnelly Hospital on its present grounds. Twenty-five thousand dollars was put aside in the 1979 Capital Budget for this purpose.

Alternatives to Institutionalization

A second area of immediate concern for this Board is the need to develop alternatives to institutionalization for those elderly persons who need help with the necessities of daily living, but who are not so infirm that they require long-term nursing care. Many of these people, whose families are unable to care for them, have no place to go but a nursing home at the present time. As a result, not only is an undue burden placed on the family or the taxpayer for expensive residential

nursing care, but the elderly person becomes prematurely dependent and often despondent when isolated from normal community living. Who among us would choose the dependence of a nursing home if one could remain independent with some help?

We, hereby commit ourselves to lend our support to viable alternatives already underway in Mercer County and to continue to explore the feasibility of new approaches being developed by experts in gerontology. These include the following:

1. Providing a County grant to Lutheran Housing, Inc. which will help provide Assistance with Daily Living Services to 40 fragile elderly persons presently on the Donnelly Hospital waiting list or referred by the Mercer County Welfare Department so that they may reside and be cared for at Luther Arms, the new HUD-subsidized housing facility for the elderly, located at Broad and Market Streets, Trenton. This grant will permit Lutheran Housing to care for 40 elderly persons for the same amount of money (\$62,000) that it would cost the County to care for 4 of these persons at Donnelly for the same period.
2. Conducting a study, included in our present Certificate of Need, of the uses to which the present Donnelly building could be put to alleviate the tremendous demand for Medicaid beds. Such alternatives would include senior citizen day care and sheltered care at the present Hamilton Township location. Senior citizen day care would permit families who are able to care for elderly family members in the evening and on weekends to bring their loved ones to the center in the morning and take them home in the evening. Persons trained in gerontology would engage these seniors in meaningful social activities

2. Continued

suitable to their age and interests. The costs for such a study are included in the 1979 Capital Budget item of \$25,000.

3. Promoting another very promising alternative form of care - Senior Citizen Family Day Care. This would require the creation of a program, under qualified auspices, which would identify and supervise homes to which the senior citizen could go during the day while a relative is at work. Again, these care takers would be instructed in the field of gerontology and visited regularly by the supervising agency to ensure optimum care of the elderly. The County should set aside money in its 1980 Title XX contingency fund for match money for this program and should vigorously lobby the State Department of Human Services to provide the necessary Title XX monies.
4. Supporting the Princeton Senior Citizen Center (for which the County obtained a federal renovation grant in 1979) with a CETA worker to provide continuity in day-time programming for seniors.

A multi-faceted program such as the one outlined above would provide services to the aging population of the County who need and deserve such services after a lifetime of useful and productive work in the community. This approach would also provide financial and emotional relief to the families of senior citizens who need some sort of support. This program would aid the cause of human dignity by allowing the elderly infirm to live with as much independence as possible, in an atmosphere of peace and safety. It would have the advantage of costing less to the community than the multiplication of full nursing home facilities, while providing for the

kind of nursing care at a new Donnelly Hospital that those who need it richly deserve.

The Mercer County Board of Freeholders urges the Mercer County Administration to proceed with these initiatives for our senior citizens immediately.

Barbara B. Sigmund James C. Hedden
 Barbara B. Sigmund James C. Hedden
 Board President Board Vice-President

Albert E. Driver, Jr. John S. Watson
 Albert E. Driver, Jr. John S. Watson
 Board Member Board Member

Frederick J. Gmitter Paul J. Sollami
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December 12, 1980

Senator Harrison A. Williams, Jr.
U.S. Senate Committee on Labor and
Human Resources
Washington, D.C. 20510

Dear Senator Williams:

Thank you for your kind letter concerning my participation in the New Jersey conference on home health care.

Those of us who have been involved in the development of effective home health resources have been aware of your commitment to these services and we, as well as the consumers who are the ultimate beneficiaries of the services, are deeply appreciative of the efforts of the Senate Committee on Labor and Human Resources and the Senate Special Committee on Aging in making the issues involved more visible through the holding of hearings such as those which were jointly held on November 23rd.

I would also like to take this opportunity to congratulate you, Governor Byrne, and Senator Bradley, for the excellence of the conference which followed the hearings. As you probably know, I have participated in a good many conferences during the course of my professional career, and I have rarely attended one which was so carefully and intelligently organized. It is unusual to meet with a group of people who are both knowledgeable and eager to act in the interests of comprehensive health services. Both Mr. Spector and Mrs. Livengood, as well as the committee, deserve commendation, for what I am certain must have involved a considerable investment of thought, time and effort in the planning of such a successful meeting.

Publication of the conference proceedings in the report of the hearings will indeed be a contribution to this field. It will provide additional support for effective policy, planning and service development. Since you have invited further comment, I am attaching a brief

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statement which supplements my remarks at the conference. If you think that the material has already been adequately covered at the hearings, please feel free to omit it.

Thank you again for your kind letter. I do indeed appreciate it.

Cordially,



Brahma Trager

BT/mm

Enc.

cc: Governor Byrne
Senator Bradley
Jed Spector
Winifred Livengood
Kathy Deignan

December 11, 1980

TESTIMONY CONCERNING ADDITIONAL CHANGES REQUIRED
IN HOME HEALTH SERVICES LEGISLATION AND REGULATION

Brahna Trager, Health Care Consultant

Medicare changes with respect to home health services included in PL 96-499 are important steps, providing for more practical and potentially more economical health care service delivery. Removal of the costly three-day hospital entry requirement, provision for improved access to the services by those with marginal income and allowance for a more realistic approach to visit "count" will greatly enhance the usefulness of these important services.

Several barriers to effective use of home health services still remain:

-- The Medicare distortion of the concept of professional "skill" eliminates the possibility of intervention through health supervision and health monitoring. Interpretation of "skill" as direct treatment (the "laying on of hands") reduces the possibility of important health care measures which could control morbidity (and cost) for a vulnerable population.

-- The Medicare concept that the initial professional visit for assessment purposes has no value which is reimbursable. This position fails to recognize the linkage between determination of need, planning for treatment and service delivery -- a linkage which is essential to the quality of care. The Medicare position is something of a paradox, in view of the current emphasis on "channelling" of consumers to appropriate resources. The initial home visit for assessment purposes

2.

is an accepted practice in all home health services of good quality. It is standard practice, following such assessment, to take the necessary action, however time consuming it may be, to take the necessary steps to arrange for care elsewhere if, on assessment, home care is not considered the treatment of choice. In this respect "channelling" is a function which is inherent in good quality home health services and reduces the need for parallel services. The financing of this visit should therefore improve the quality of coordination as well as protect continuity in the provision of home health care.

-- The arbitrary division in paraprofessional services (Home Health Aide, Homemaker, "Chore", etc.) which allows for Medicare reimbursement only for the "Home Health Aide" function, fragments an important element in the home care sequence. Effective paraprofessional services are those in which there is a flexible flow of functions between those involving personal care, those involving maintenance of a supportive environment, those involving observation, and those involving healthy interpersonal relationships. The splitting of these functions between a variety of paraprofessionals with different titles reduces the effectiveness of all of them and creates costly duplications.

-- The effectiveness of any part of the health care delivery system is affected by the degree to which it is accessible, available and so organized that it is capable of providing adequately for the range of services required by the target population. At the present time, home health services in the U.S. are deficient in all of these aspects. Policy, planning, funding, and implementation of a long-



State of New Jersey

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GERALD J. REILLY
 Deputy Commissioner
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 Deputy Commissioner

ANN KLEIN
 Commissioner

December 17, 1980

The Honorable Harrison A. Williams, Jr.
 Senator
 352 Russell Senate Office Building
 Washington, D.C. 20510

Dear Senator Williams:

Thank you very much for this opportunity to enter additional comments pertinent to the November 24, 1980 Governor's Conference on Home Care into the records of the Senate Committee on Labor and Human Resources and the Special Committee on Aging.

I would like to clarify an important statistic which was incorrectly alluded to at the conference, thus unintentionally perpetuating an all-too-common misconception regarding the proportion of nursing home patients who are "unnecessarily" or "inappropriately" institutionalized. Several speakers made statements to the effect that, "over thirty percent of New Jersey nursing home patients do not need to be in nursing homes", usually citing "a study done for New Jersey Medicaid". Such claims, although well intended, considerably overstate the incidence of inappropriate nursing-home placement.

The study pointed to was, in fact, a 1977 study done for our Division of Medical Assistance and Health Services by the Urban Health Institute. It involved in-depth reviews of approximately twenty-five percent of all Medicaid patients at the Intermediate Care Facility level B (ICF-B) receiving nursing home recertifications over a three-month period. ICF-B corresponds to level IV-B, a level of care providing minimal nursing and residential services to those for whom living in the community is judged impractical, but who are not sick or disabled enough to require skilled or higher level intermediate nursing services. ICF-B or IV(B)

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 SENATOR
 HARRISON A. WILLIAMS, N.J.
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is the lowest level of institutional long-term care covered by Medicaid. It was selected for examination because, by definition, ICF-B patients are closest to the need for alternate care and most likely to provide accurate indicators of the types of alternate settings and services required in New Jersey.

Other levels of long-term care in New Jersey are SNF or Level III, which involves skilled nursing care for persons with acute or sub-acute medical or mental dysfunctions requiring continuous skilled nursing care, and ICF-A or Level IV(A), the upper level companion to ICF-B. Upper level ICF-A patients are judged to require substantial assistance with personal care needs on a daily basis rather than the minimal assistance required in ICF-B.

The study concluded that thirty-five percent of those patients at the ICF-B level could be discharged if appropriate lower levels of care were available to them; that is, thirty-five percent of ICF-B, not all nursing home patients. And, since ICF-B comprises about twenty-two percent of all Medicaid nursing home patients (ICF-A about seventy percent and SNF about eight percent), the figure implies that actually only about seven to eight percent of all nursing home patients possibly could be discharged if appropriate lower levels of care were available. Thus, incorrect interpretations of the data have lead to a considerable exaggeration of "unnecessary" or "inappropriate" institutionalization.

Still even seven to eight percent is too high, and we must strive to develop and implement policies that will enable those clients to have access to lower levels of home and non-institutional care. Not only would the discharge of those seven to eight percent into lower levels of care comply with our fundamental principle of least restrictive, most efficient, humane, and appropriate care, it would also make available those nursing home beds for patients on our 3,000-person waiting list who truly require institutional care.

To this end, we have vigorously supported H.R.-6194, "The Medicaid Community Care Act of 1979" as well as other remedial legislation. H.R.-6194 focuses precisely and effectively on that element of the Medicaid reimbursement system - the Community Cap - that perversely ensures unnecessary institutionalization. Our efforts at the State level cannot succeed until that disincentive is addressed.

Again, thank you very much, Senator Williams, for this opportunity to clarify a frequently misunderstood and misused statistic.

Sincerely,

A handwritten signature in cursive script, appearing to read "Ann Klein".

Ann Klein
Commissioner

AK:8

STATE OF NEW JERSEY
DEPARTMENT OF COMMUNITY AFFAIRS
DIVISION OF AGING

1980 CONFERENCE, :
: TRANSCRIPT
HOME - HEALTH CARE : OF
: PROCEEDINGS
IN NEW JERSEY :
: VOLUME I
-----*

Educational Testing Service
Henry Chauncey Center
Carter Road
Rosedale, New Jersey
Monday, November 24, 1980
9:00 a.m. - 4:00 p.m.

S P E A K E R S:

SENATOR BILL BRADLEY

GOVERNOR BRENDAN T. BYRNE

BRAHNA TRAGER, Health Care Consultant

P A N E L I S T S:

RITA K. DE COTIIS, Executive Director, Nursing
Service, Inc.
President, Board of Directors
Home Health Agency Assembly of
N.J., Inc.

LEIGHTON E. CLUFF, M.D., Executive Vice-President,
Robert Wood Johnson Foundation

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of Human Services

MARTHA DARLING, Legislative Assistant to Senator
Bradley

A L S O P R E S E N T :

JED SPECTOR, New Jersey Department of Human Services,
Division of Medical Assistance and
Health Services

JUDY LYNN FLOWER, C.S.R.

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MR. SPECTOR: Good morning. If everyone will find a seat, please. I'd like to welcome you all to the first New Jersey Conference on Home-Health Care and I would like at this time to introduce to you the Governor of the State of New Jersey, the Honorable Brendan T. Byrne.

Bill Bradley will speak first before Governor Byrne. Also, the prepared remarks of Senator Harrison A. Williams, Jr., who had to return to Washington earlier today, will be printed in the record.

(Senator Williams' prepared remarks follow:)

REMARKS BY SENATOR HARRISON A. WILLIAMS, JR.
BEFORE THE GOVERNOR'S CONFERENCE ON HOME HEALTH CARE
HENRY CHAUNCEY CONFERENCE CENTER
ROSEDALE ROAD
PRINCETON, NEW JERSEY

MONDAY, NOVEMBER 24, 1980

IT IS A PERSONAL PLEASURE FOR ME TO JOIN YOU TODAY TO PARTICIPATE IN THIS SPECIAL CONFERENCE ON HOME HEALTH CARE POLICY. THE ISSUE OF HOME HEALTH CARE HAS BEEN OF SPECIAL CONCERN TO ME FOR MANY YEARS.

I WANT TO COMMEND GOVERNOR BYRNE FOR SPONSORING THIS EFFORT. THIS CONFERENCE DEMONSTRATES THE PRIDE WE FEEL IN THE STATE OF NEW JERSEY FOR TAKING THE LEAD IN THIS CRITICAL AREA OF NATIONAL POLICY.

YESTERDAY, THE COMMITTEE ON LABOR AND HUMAN RESOURCES, WHICH I CHAIR IN THE SENATE, TOGETHER WITH THE SENATE SPECIAL COMMITTEE ON AGING HELD A HEARING ON THIS ISSUE IN CONJUNCTION WITH TODAY'S CONFERENCE. BECAUSE OF MY FEELING THAT THIS ISSUE IS OF NATIONAL IMPORTANCE, I HAVE MADE ARRANGEMENTS TO KEEP THE COMMITTEES' HEARING RECORD OPEN SO THAT THE PAPERS AND TRANSCRIPTS OF THIS CONFERENCE CAN BE INCORPORATED AND PRINTED IN THE FINAL RECORD FOR THE USE OF CONGRESS.

LEGISLATION THAT WOULD REVISE OR EXPAND HOME HEALTH CARE SERVICES WILL BE AN IMPORTANT ITEM ON THE AGENDA OF THE NEW CONGRESS, WHICH BEGINS IN JANUARY. I AM ENCOURAGED TO SEE THAT THE URGENT NEED FOR ACTION HAS FINALLY BEGUN TO GAIN THE RECOGNITION IN CONGRESS THAT WE HAVE BEEN SEEKING FOR NEARLY A DECADE.

IN THE PAST WEEK, CONGRESS APPROVED AMENDMENTS TO THE MEDICARE HOME HEALTH PROGRAMS UNDER THE 1980 BUDGET RECONCILIATION BILL. THIS LEGISLATION WILL PERMIT AN UNLIMITED NUMBER OF HOME HEALTH VISITS PER YEAR UNDER PARTS A AND B OF THE MEDICARE PROGRAM. THE AMENDMENTS WILL ELIMINATE THE 3-DAY PRIOR HOSPITALIZATION REQUIREMENT UNDER PART A, AND WILL ELIMINATE THE \$50 DEDUCTIBLE PROVISION FOR HOME HEALTH UNDER PART B. THE BILL ALSO REQUIRES AN APPROVED TRAINING PROGRAM FOR HOME HEALTH AIDES.

OTHER AMENDMENTS UNDER THE RECONCILIATION BILL REQUIRE THAT "MEDICARE-ONLY" HOME HEALTH AGENCIES ESTABLISH BONDING OR ESCROW ACCOUNTS. THE DEPARTMENT OF HEALTH AND HUMAN SERVICES IS REQUIRED TO ESTABLISH REGIONAL INTERMEDIARY OFFICES FOR HOME HEALTH AGENCIES TO COORDINATE SERVICE PROGRAMS AND TO PROVIDE TECHNICAL ASSISTANCE.

A NUMBER OF OTHER LEGISLATIVE PROPOSALS WERE INTRODUCED IN THE CURRENT SESSION OF CONGRESS. ONE, WHICH I SPONSORED, WOULD AMEND THE SOCIAL SECURITY ACT TO PROVIDE A NONINSTITUTIONAL PROGRAMS OF COMMUNITY-BASED, LONG-TERM CARE SERVICES FOR THE ELDERLY AND THE DISABLED.

THIS BILL WOULD CREATE A NEW TITLE XXI OF THE SOCIAL SECURITY ACT BY COMBINING ALL HOME HEALTH AND IN-HOME SERVICES WHICH ARE CURRENTLY UNDER MEDICARE, MEDICAID, AND THE TITLE XX SOCIAL SERVICE PROGRAMS.

IT WOULD ESTABLISH A TEAM OF INDIVIDUALS REPRESENTING NURSING, SOCIAL SERVICES, ADVOCATES FOR SENIOR CITIZENS AND THE DISABLED, AND OCCUPATIONAL THERAPISTS, ALL UNDER THE GENERAL DIRECTION OF A PHYSICIAN. THIS TEAM WOULD SCREEN, ASSESS, AND ESTABLISH A PLAN OF CARE FOR PERSONS RECEIVING BENEFITS UNDER THE NEW TITLE.

THE LEGISLATION WOULD HELP PROVIDE AN ORGANIZED SYSTEM OF MEDICAL AND SOCIAL SERVICES FOR THOSE LIVING IN THE COMMUNITY AS OPPOSED TO PERMANENT CARE INSTITUTIONS. IT CALLS FOR SKILLED NURSING CARE, RESPITE SERVICES, HOMEMAKER AND HOME-HEALTH AIDES, AND PHYSICAL, SPEECH, AND OCCUPATIONAL THERAPISTS FOR THOSE IN NEED OF SOME ASSISTANCE.

IN ADDITION, THE BILL WOULD DROP CERTAIN UNNECESSARY REQUIREMENTS FOR AN INDIVIDUAL TO QUALIFY FOR SUCH NEEDED SERVICES. IT WOULD ENCOURAGE LESS DEPENDENCE ON HOSPITALIZATION AND NURSING HOME CARE AND WOULD SPUR THE DEVELOPMENT OF DAY CARE CENTERS FOR SENIORS.

I VIEW THE INTRODUCTION OF THIS BILL AS AN IMPORTANT FIRST STEP TOWARD GENERATING A NATIONAL DEBATE ON THE PROVISION OF HOME HEALTH CARE. I SPONSORED IT KNOWING THAT WE MAY NEED TO ADJUST OR IMPROVE THE LEGISLATION. BUT, THERE IS LITTLE DOUBT THAT ALL OF US, NOT JUST SENIORS, WILL BENEFIT FROM THIS EFFORT.

CURRENT MEDICARE AND MEDICAID BENEFITS COVER ONLY A SMALL PORTION OF THE SERVICES USUALLY NEEDED TO MAKE HOME CARE A VIABLE OPTION. THE OLDER AMERICANS ACT PROVIDES THE ASSISTANCE NECESSARY FOR NUTRITION PROGRAMS AND SOCIAL SERVICES, BUT CANNOT FULLY SERVE IN-HOME NEEDS.

DATA RECENTLY MADE AVAILABLE TO THE CONGRESS FROM THE DEPARTMENT OF HEALTH AND HUMAN SERVICES INDICATES THAT PUBLIC AND PRIVATE SPENDING ON HOME HEALTH AND LONG-TERM CARE HAS DOUBLED SINCE 1965 AND WILL DOUBLE AGAIN BETWEEN 1980 AND 1985. PUBLIC EXPENDITURES FOR NURSING HOME CARE ALONE WAS \$800 MILLION IN 1965 AND IS EXPECTED TO REACH OVER \$9.0 BILLION BY 1984.

AS THE PROPORTION OF OLDER AMERICANS IN THE UNITED STATES CONTINUES TO GROW DURING THE COMING DECADE, THE ISSUE OF HOME HEALTH CARE AND IN-HOME SERVICES WILL BECOME MUCH MORE IMPORTANT, AND OUR RESPONSE WILL HAVE TO BE MUCH MORE DIRECT AND COMPLETE.

IN OUR DISCUSSIONS TODAY WITH THESE EXPERT PANELS, WE SHOULD CONSIDER FEASIBLE CHANGES TO EXISTING PROGRAMS THAT WOULD MAKE AVAILABLE A WIDER RANGE OF HOME HEALTH CARE AND LONG-TERM CARE OPTIONS TO THOSE PERSONS AT RISK OF ENTERING AN INSTITUTION. WE SHOULD CONTINUE TO SEEK A COMPREHENSIVE PROGRAM OF SERVICES AND TO DEVELOP BETTER METHODS FOR FUNDING AND REIMBURSEMENT.

WHEN WE CONSIDER THE OPTIONS FOR FINANCING HOME HEALTH, WE SHOULD BE CAREFUL TO PRESERVE THE ROLE OF FAMILIES AND OTHER VOLUNTARY SUPPORT GROUPS. WE SHOULD CONSIDER ALTERNATIVES TO THE PRESENT DISINCENTIVES WHICH OFTEN PREVENT INDIVIDUALS WHO WANT TO STAY AT HOME FROM FINDING AND PAYING FOR THE SERVICES NEEDED TO MAKE THAT CHOICE A REALITY.

COMMUNITY ORGANIZATIONS THAT PROVIDE IN-HOME SERVICES HOLD THE ULTIMATE RESPONSIBILITY FOR THE QUALITY AND EFFICACY OF DELIVERY UNDER THE DIRECTION OF STATE AND LOCAL AGENCIES ADMINISTERING FEDERALLY ASSISTED PROGRAMS. WE SHOULD CAREFULLY DEVELOP A SYSTEM THAT WOULD ENCOURAGE THESE PROVIDERS TO WORK TOGETHER TOWARD THE COMMON GOAL OF QUALITY CARE, RATHER THAN A SYSTEM WHICH WOULD ENCOURAGE

FACTIONS AMONG COMPETING INTERESTS. TO ACHIEVE THIS, EXTENSIVE AND PERHAPS FUNDAMENTAL CHANGES MAY WELL BE REQUIRED IN THE WAY WE ORGANIZE, DELIVER, AND FINANCE CARE FOR PERSONS WITH IN-HOME HEALTH NEEDS.

ANOTHER CRITICAL ISSUE THAT WILL HAVE TO BE ADDRESSED IN ANY DISCUSSION ABOUT THE FUTURE OF COMPREHENSIVE CARE IS THE ISSUE OF PERSONNEL. HOW CAN WE INSURE THAT AN ADEQUATE NUMBER OF TRAINED AND DEDICATED PERSONNEL WILL BE AVAILABLE FOR THE HOME CARE SYSTEM? WHAT OPTIONS SHOULD WE CONSIDER SO THAT SCHOOLS COULD DEVELOP OR EXPAND HEALTH PROFESSIONS TRAINING PROGRAMS RELATED TO HOME HEALTH SERVICES?

I AM ANXIOUS TO REVIEW IN MORE DETAIL THE RECOMMENDATIONS THAT WILL RESULT FROM THIS CONFERENCE. AND, I AM GRATIFIED THAT I SHARE WITH OUR DISTINGUISHED PANELISTS IN THIS EFFORT THE OVERRIDING CONCERN THAT THESE PROPOSALS BE AIMED AT PRESERVING THE DIGNITY AND INDEPENDENCE OF THE ELDERLY AND DISABLED IN THE DEVELOPMENT OF PUBLIC POLICY.

THE 1980'S WILL BE A TIME OF NEW CHALLENGES TO BUILD ON THE GAINS WE HAVE MADE. OUR EFFORTS ON BEHALF OF OLDER AND DISABLED AMERICANS, NOW, WILL ENHANCE THE QUALITY OF LIFE FOR US ALL, AND WILL SECURE OUR PRIDE AS A NATION.

#

SENATOR BRADLEY: I'm not the Honorable Brendan T. Byrne. I'm your Junior Senator from New Jersey, Bill Bradley, and I want to say that I am pleased to be here today to join Governor Byrne and Senator Williams in sponsoring the proceedings of this conference which will be a part of the official Senate record.

Yesterday, Senator Williams and I conducted hearings on home-health care in New Jersey. From an academic perspective I found them extremely helpful. These will also be a part of the hearing record of the Labor and Human Resources Committee, the Aging Committee, and the Finance Committee.

From the list of participants this conference looks to be a very fruitful one.

Bradley

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We have some of the most able people in the country in home health care here in the audience and I hope with that kind of experience you will be able to focus on the critical issues in home-health care and help those of us who are trying to legislate laws write them wisely.

Too many people today, too many elderly and disabled, in my judgment, have no choice when it comes to treatment. They are either pushed into a nursing home, into an institution, or they go without care. About 15 percent of the elderly are either bedridden or require assistance in basic functions of living. About a third receive some kind of Government Assistance. Many others can't afford any kind of service.

In our reimbursement policy there is a strong bias, as most all of you know, toward institutional care and I think that it has created unacceptably high cost for both State and Federal budgets.

For example, last year \$8.5 billion in Federal dollars went to nursing homes. \$1.5 billion in Federal dollars went to home care ser-

Bradley

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vices. Now, somewhere between 15 and 40 percent of all institutionalized individuals don't have to be in those institutions.

If that isn't a startling enough fact, we only have to add one other that comes much closer home, and I'm sure Governor Byrne will talk about it in greater detail, and that is, we here in New Jersey and also other states have reached the limit on our Medicaid budgets. Indeed, Medicaid faces a possible bankruptcy situation in the State of New Jersey next spring unless very serious action is taken.

So with that kind of background, your charge as participants in this conference is very important because what we need to do is develop a plan of action for New Jersey and for the country concerning home-health care services.

I think that we all already agree that the expanding availability of home-health care services is a desirable goal. I think we can achieve that goal and I've committed myself to achieve it. Senator Packwood and I have introduced a bill, S-2809.

Bradley

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It's the Noninstitutional Long-Term Care Bill. In negotiations between Senator Packwood and me prior to introduction, we were concerned that we not leap into another extremely large Federal program without knowing where we were going, so one of the parts of our bill is the demonstration phase. It will create ten statewide demonstrations across this country

to test some of the concepts which you will hopefully develop in conjunction with the other people who are contributing to this record. They will allow us to see if, indeed, home-health care can lead to deinstitutionalizing people, to assessing some level of demand for home-health care services.

Yesterday, for example, one of the witnesses concluded what I felt was a different message than I had heard-- that the cost per individual in home-health care versus institutionalizing the individual will be less, but the overall Federal cost will be more, because as soon as home-health care is open, you suddenly have opened up populations that you never thought before were in need of medical care. We also want to recognize in the bill that each state is different, and has its own way of

Bradley

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delivering home-health care services, but that the need to organize this delivery system on a state-wide basis is absolutely essential.

Some of the providers who were there yesterday, people in the front lines in Union County and Essex County, were quite adamant on the danger and the difficulty of trying to administer the fragmented system that we have out there today. So what we want to do, Senator Packwood and I -- Senator Williams was also a co-sponsor -- is to concentrate into a new title, Title XXI of the Social Security Act, the home-health care services that are now available, to make it an expanded service, to take into consideration the differences among states, and to do it in a demonstration context so we can test the delivery systems and the reimbursement patterns.

Our thought is to make this a five-year demonstration so that once you get used to the waivers that are embodied in the demonstration, you don't have them yanked back at the end of one year and then you're back to the old system. Instead you have five years in which to test the viability of a new Title XXI of the

Social Security Act.

Although I will not be here for the rest of the conference, I'm looking forward to reading the record and to hearing your suggestions. Because in these matters I, as a member of the Finance Committee that will be writing the law, will rely very heavily on your experience. To the extent that your experience is in New Jersey, that means that it's even more positive from my perspective because you are the people to whom I am most accountable.

I appreciate the opportunity to come by and say hello to you. I apologize that I won't be here for the rest of the session, but I do have staff members, Martha Darling and Dennis Marco, who will be here and will report back to me in full. I have to deal with another health-related matter and that is the Super Fund legislation that comes up on the floor, hopefully today around one o'clock, and I have to leave.

I want to thank you very much for inviting me and for holding this conference. I'm glad to be a part of it. I look forward to reading your contribution which I think will be significant in helping us frame the proper legislation in

Bradley

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the coming session.

Thank you.

MR. SPECTOR: We home care people are about to demonstrate our large degree of flexibility, so without further introduction, the Honorable Governor Byrne.

GOVERNOR BYRNE: Thank you. I was anxious to have Bill Bradley get to Washington, frankly, because that super fund for chemical wastes is very important. There is no state that needs it more than New Jersey, and there's no Senator that's taken the leadership more effectively than Senator Bradley has so I'm always happy to let him get to Washington and bring back the super fund to New Jersey.

It's nice to be back here. Just before you came in yesterday there was a group that left and I was with them for part of the time dealing with how the Government officials get along with the press and that was an interesting few hours. Ed Koch came down for that one. I don't know if he had left by the time you got here last night. He doesn't get to New Jersey very often. When he does, I enjoy teasing him.

Byrne

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I accused him of asking me whether when he comes to New Jersey he can bring stuff back to New York duty free. That just started off a little discussion between Ed Koch and myself here.

I also told him that we rejected the water that New York offered to supply us when we found out it was diluted. That took him a minute or two.

I told him we were very gracious in New Jersey. We let him come over from New York free and it costs him a dollar-and-a-half to get back. He may not show up again for awhile in New Jersey.

We had a great time and back again this morning and I have to shift gears. I'm here often enough. I'm reminded of the story of the 94-year-old fellow who went to the funeral parlor to pay his last respects to a departed friend and the funeral director looked at him and said, "It's hardly worth your while to go home."

I've been here often enough over the week-ends that it's hardly worth my while to go home. I was anxious to come and I'm proud of the attendance here and the quality and turnout and the problem you're attacking.

Let me first put your problem in a political

perspective and to say very honestly from where I sit, there's probably no political plus in any program which involves the delivery of services. If you build a building, you get a lot of political credit. If you build a turnpike or a big highway or a large building for health care delivery, that's where you're going to get the political credit.

If you staff the building, if you improve the quality of services in the building, you do not get much political plus out of it, and I report that just as a political fact of life and also I would report it as a challenge to you because I think one of the things that you've got to do as leaders in the field is to build a constituency for care. We don't have it in the State today and we don't have it in the United States today.

A constituency for care. I would hope that that would be on your agenda, if not for this meeting, as a continuing role in your responsibility as leaders in the field. I guess if you ask the rhetorical question, "What's new," you would get the more interesting answers in the health care field than almost anywhere else, and

Byrne

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if you ask the question, "What's new in New Jersey," I think we can document significant leadership in the field of health care, home-health care and hospital health care with various programs, many of which are controversial.

Hospital costs continue and diagnosis-related payments to hospitals, various out-patient approaches, a number of different, and I think enlightened in ways, of treating patients outside of hospitals, local clinics. I was in East Orange a week ago Sunday for the dedication of one in East Orange General Hospital.

In emphasis on that type of treatment which prevents sickness, I do think that New Jersey has shown leadership in that regard and I know you'll hear more from Commissioner Finley who's here and from Chancellor Hollander who's here and from other members of State government.

Now, we're not without controversy, either, as an administration in general. As a matter of fact, I sort of thrive on controversy and am used to it, if I don't thrive on it. I like to tell people about the lady who wrote to me and said, "Don't worry, Governor. Your accomplishments will outlive you, and I hope soon," she said.

Byrne

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Some of the things you try don't work, but I think that the fear that it won't work shouldn't and frankly in a State like New Jersey, can't be the reason for not trying, so that you, I believe, meet this morning in a good climate, a climate of a State that's willing to listen to you; that's willing to be innovative; that's willing to dare; to make a mistake if in taking the chance, the chances for success appear to be better than the chances for failure.

So I, too, am interested in the result of your deliberations here, and I just hope that as a result of those deliberations, we can find ways to improve, some new directions, and some methods of mobilizing a little more public support for what we're doing. But whether or not we mobilize the purchase support, the basic bottom line is to do what's needed and to do what's right, and I believe that they will be your guideposts in your efforts today.

Thank you.

MR. SPECTOR: Thank you, Governor Byrne. At this time it gives me great pleasure, once again, to introduce our key note speaker for the day, Brahma Trager.

Trager

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Brahna Trager has been a professional in home-health care and long-term care for many years. She is the author of three reports to the Special Committee on Aging of the United States Senate. She has also written texts for publication for the Department of Health, Education, and Welfare, now H.H.F. and she's been the author of numerous articles and reports in home-health care and related fields.

Brahna has been an administrator of a home-health services' committee to long-term care and was administrator of the Crippled Children's Services in California State Department of Public Health for a number of years. She has participated in research projects related to non-institutional community services and has served as a consultant and advisory board member in various state and local projects.

And most recently Brahna has become co-publisher of the Home-Health Care Services' Quarterly, and I'm proud to bring you today Miss Brahna Trager.

MS. TRAGER: Thank you very much. It was kind of reassuring to hear those remarks, I thought.

ager

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So often the public people, people who seem to represent us, act as though they had never really heard of home-health services before and it was nice to find at least that degree of sympathy and comprehension about the need in a group like this.

I guess we can start on a little bit more of an upbeat even though some of us have in recent months been feeling a little bit depressed about the service program altogether. I couldn't agree more about the Oedipus complex that makes everybody want to have a building instead of a bunch of services and I often say that you can administer home-health services out of a tent. They can be very, very good, too. You don't need buildings and you don't need rugs and you don't need a Bigelow on the floor and your name on the door to do it with.

Home-health services do belong in a gray area of our health delivery system, in part because they're relatively new in the United States, and in part because they've been poorly understood. The limitations and understanding have been influenced by the way that the services have been defined, and by the fact that they've been incorrectly presented as an alternative to, and therefore,

competitive with, institutional services which have had a great deal more status and a far better financial base, although it could be said that institutional services have to some extent been misunderstood.

The fact remains that home-health services have not achieved a position of high priority in public policy. As a result the potential of a set of services which could be of great importance to significant sections of the population have not been realized.

One of the interesting aspects of this situation is that one cannot accuse the planners, the policy makers, legislators, or the community organizers of indifference. No, indeed. Whenever the issue of the increase and the costs of other methods of care arises, when the high cost of hospital care or the increased utilization of long-term care institutions are considered, the head shaking and the gloomy predictions about the increased lifestyle which should be a matter for rejoicing are accompanied by a renewed interest in cost control measures, and in this context, home-health services do have a high priority, at least in verbal discussion.

Along with considerations of capping costs, the circular issue of home-health care as an alternative to institutional care comes around again. While it is true that the values which might be achieved by providing care in the home and community are invariably stressed, the overriding consideration is, of course, the issue of cost.

The question that is paramount simply phrased is this: How can care be provided which is cheaper than the care that is being provided in the present system of services? Of course, we're not inhumane. We're not indifferent to such important issues as quality and acceptability. We would like the cheaper care to be as good or even better than what is now being provided, particularly for the disadvantaged sections of the population who are now accounting for a fairly large percentage of the health social budget in the United States and who may, with projected demographic changes, and inflation, increase that percentage in the future. But these more humane considerations tend to get lost in the weighing of cost control measures.

Since the use of home-health services almost invariably enters into such considerations,

it is surprising that the development, the scope, the utilization, and the position of the services have not changed very much since the major source of reimbursement, publicly funded insurance for home-health care, became available in 1965. The bulk of home-health services are Medicare reimbursed.

Medicare expenditures for home-health services in 1969 amounted to 1.2 percent of total expenditures. In 1977, that is 12 years after Medicare reimbursement became available for home-health services, Medicare expenditures for these services amounted to 1.8 percent of total expenditure, hardly a stunning record of growth.

Medicaid expenditures for home-health services, which are intended for the poorest section of the population and probably the sickest, amounted in 1977 to about 1 percent of the same year. For that year, Medicaid's share of nursing home expenditures amounted to more than 89 percent of public personal health care expenditures, more than \$6 million excluding skilled care and intermediate care facilities.

The picture of home-health care is much the same for service availability. In 1969 there

were approximately 2200 Medicare certified agencies in the United States. Ten years later, this number had increased by slightly more than 500 agencies, a total of 2,788 certified agencies, concentrated mainly on the two coasts and in heavily populated urban areas with little or nothing elsewhere.

It is rather difficult in these circumstances to support a conclusion that there is, indeed, great interest in home-health services, either as a health resource, a social resource, or as an alternative to other care for the population. It's difficult to understand why this should be so. Why do these services which seem to offer so much not have the same rapid development and the same utilization patterns as other services in the health delivery system?

When Gertrude Stein, a somewhat esoteric but influential American writer, was at the end of her life, she was heard to ask, "What are the answers," and after a pause she asked, "What are the questions?"

Perhaps that exchange would be a good part of the departure in the present discussions, for it does appear that the difficulties may lie in the fact that we have consistently chosen to

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look for the answers before we have asked the questions or perhaps it is that when we have asked the questions, they have not been directed to the central problems and have produced answers which more often than not have been irrelevant.

It might be relevant, for example, to go back to the first questions lost sight of in the abundant and frequently confusing discussions that we've been hearing over the past eight years, questions which might be directed to home-health services' objectives. What should the services do? Who needs the services? They might be directed to service definitions. What are home-health services and how are they defined?

While for most of us who are or who have been providers, people and service objectives usually come first. Our situation is so much affected by the quality of public understanding which the Governor just spoke about that it might be well to restate the definitions for the record.

What are home-health services? In a simpler time when families stayed together, when few women worked outside the home, when unmarried sons and daughters remained at home to take care of sick family members, when one of the occupations

or vocations of many middle and upper class women was to visit the sick, poor, providing health and comfort, and when the family doctor added charitable home visiting to his daily round, home care was perhaps, it seems in retrospect, a simple thing which might be easily replicated today in our industrialized society. Whether it was reliable and of good quality is something we can't really judge.

In any case, though we hear today a good deal about formal care, the care provided by family members, we do know that it is often provided at great personal cost; that family members and entire family constellations might be destroyed by the heavy burden of care of those who are sick or functionally impaired.

A family itself is different today. Many of those who are most in need have no effective family support or have no families at all. The family doctor does not visit the home and the women who formerly provided health and comfort are now doing other things, usually working for a living. If this were not so, we would not have an institutional industry today.

As a matter of fact, the beginnings of

the modern version of services in the home was not at all a nostalgic attempt to replicate former times. It was an intelligent professional effort to achieve better therapeutic results.

The first home care as a professional outgrowth of this effort developed in the United States in the early 1940's. It was a coordinated, formerly organized set of services, initially hospital based. It provided a very wide range of services in the home, supplemented by visits to the hospital or the outpatient clinic as necessary. The therapeutic considerations in this effort were based on the observation by health professionals that many people did not get well as quickly as they should in institutional settings.

At either end of the age spectrum, children and older patients did poorly in hospitals, particularly when hospitalization was prolonged. While early discharge was a common practice with children, older people tended to require longer stays. Therefore organized or coordinated home care programs had quite different objectives from those that are prevalent today.

Their standards, the pattern, and scope of the care provided were primarily directed to

improved therapeutic outcomes. Economy was not a primary objective, though they appeared to have certain cost advantages as well. Although the home care movement started in hospitals, they became attractive as free-standing community programs as well. Some of them attached to health departments, some to visiting nurse services, and some established as independent community services.

These programs provided what it was determined that the consumer required in the way of services, provided that the plan was feasible. The American Hospital Association identified 15 services which should be available to the consumer at home. There was sound reasoning in this instance on a wide range of services.

It recognized the fluctuating nature of both acute and chronic illness and various levels of disability. It recognized as well the fact that there are differences in consumers at all ages and that these differences are frequently accentuated in periods of illness and disability, and while few individuals might need all of those services or might not need them all of the time, it is important to good care that the right services should be available in the right combination and

at the right time since arbitrary limitations could make an important difference in what happened to the consumer and to the future course of his illness.

Very few of these programs make distinctions about age or about the duration of care and presumably the programs were considered effective and continued to grow. When service definitions were developed as they usually are in a new service, they were based on some basic principles, all of them encompassing the therapeutic objectives of home-health care. These principles defined the services as organized; that is, having a sound administrative base, as coordinated; that is, providing for linkage of the components of care in an effective combination, and comprehensive; that is, including all of the professional, paraprofessional, and related services and equipment essential in the home. The care was to be characterized by its continuity; that is, the assumption of responsibility for the duration of the need.

The pattern of delivery was in these definitions based on assessment of the illness and its care requirements of the consumer and the

family, if there was one, and of the environment in which the care was to be provided; that is, the feasibility of the home and the willingness of the people who lived in it to receive this method of care. The care was considered appropriate to people of all ages. These elements have been retained in all professional definitions, the most recent formulated by the major national organizations involved in the provision of home-health services.

Its general outlines are as follows: Home-health services are that component of comprehensive health care whereby services are provided to individuals and their families in their place of residence for the purpose of promoting, maintaining, or restoring health or of minimizing the effects of illness and disability; so this is appropriate to the needs of the individual patient and family are planned, coordinated, and made available by an agency or institution; the services are provided under a plan of care that includes but is not limited to appropriate services components, such as medical care, dental care, nursing, physical therapy, speech therapy, occupational therapy, inhalation therapy, social work, nutrition, home-

maker home-health aide services, transportation, laboratory services, medical equipment and supplies. This definition is intended to meet most situations in which it might be feasible to maintain any individual of any age at home with care adapted to the needs of the problems of the illness and disability. If today one were to ask the average health professional or legislator or even the average home-health services' provider to give a definition of home-health services, the answer would sound something like this:

Home-health services are a part time intermittent service provided to Medicare insured people who are housebound but not custodial and who require skilled nursing services, and at least one additional service, possibly for some physical therapy or occupational therapy or some limited home-health aide services provided that these are primarily restricted to physical patient care.

This description illustrates a point. Prevalent understanding of home-health services today has little or nothing to do with an accurate service definition. It is a description of an insurance benefit, the Medicare insurance benefit,

which have also been adopted by Medicaid. It is also the home-health benefit which is sold by private insurance when home-health is included in an insurance policy.

There is, therefore, a clear distinction to be made between home-health services of good, usable quality, and an insurance benefit which offers a few selected services delivered in the home under restricted conditions. This difference in definition is of great importance. It has influenced public understanding and it explains the confusion and consequently the limited financial support available for home-health services. It provides at least one answer to the problem of the very limited utilization of the services. Home-health services have not been used because they have not been very useful in their present form as that form is defined by the major funding sources, and while one could ask why the public at large does not use or support more flexible services, the answer would be, which would come closest to the truth, would be that most home-health service agencies today do, in fact, limit the services they offer to fit the insurance benefit since there is very little alternative

funding available.

The services have been skewed to the funding sources and this distortion has reduced the usefulness of the service. This suggests a related question, what services should be available to people if they are to be cared for effectively at home? The answer is, of course, that ideally the broadest possible range of services should be available.

In periods following acute illness in a short stay at the hospital, early discharge would be more feasible if selection from at least five or six home delivered services could be made in combination as needed for care. But even within the range of services with which are presently reimbursable, a change in reimbursement policy with respect to the functions of home-health personnel could make a great deal of difference in the usefulness of the services and in appropriate service utilization. These changes are mainly of a practical nature.

General experience with utilization indicates that a major barrier to effective use is the application of the definition of skill in Medicare. In nursing, for example, which is one

of the primary services, the present requirement is that it must be what has been described as hands on nursing; that is, nursing in which some direct treatment is provided. Such nursing functions as the monitoring of patient care, the supervision of patient progress, the establishment and maintenance of treatment regimes are not considered skilled for reimbursement purposes. These functions in nursing care are, however, the very core and essence of nursing skill and probably the most important to the principle that the level of care provided should be commensurate with consumer need.

The fact that supervision and monitoring cannot now be made available has had something to do with the reluctance of referral sources to consider home-health services seriously. A similar restriction exists in reimbursement policies for the use of other professional services for reinforcement, supervision, and monitoring by physical therapists, occupational therapists, and social workers. Preventive intervention is a key element in the control of morbidity, particularly in situations in which illness has a high potential for future long-term impairment, and this is not

available at present in home-health services.

A second barrier is one which places on the consumer the burden of maintaining the personal environment during periods of illness. Reimbursement regulations require that paraprofessional functions be divided into two separate areas, those that require as in the case of the professional the laying on of hands, which are considered health related services and are reimbursable; and those which have been classified under at least a dozen titles, all of them ineligible for Medicare reimbursement because they are considered social.

The many successful home care programs which are almost universally available to the populations of western European countries have always relied heavily on the use of paraprofessionals and this level of service from a practical point of view is the backbone of effective home care. Paraprofessionals simplified the problems of caring for the sick and impaired who live alone. They help to solve the problem of sick members in multi-problem families. They relieve the strain of care in intact families in which a family member may have an acute or long term health problem.

The combining of responsibility for physical

care with the maintenance of the living situation so that both the hands on functions of the health aide and the environmental support provided by the homemaker could be assumed by the same person would make for a less nonsensical and a more economical pattern of service and establish trust in service effectiveness.

While it is not related to the range of services provided in current programs, effective utilization has been greatly hampered by the part time intermittent requirement for service in Medicare which other home-health requirements have always been adopted in Medicaid. While most home-health care is used in a pattern of part time intermittent service, the necessity to restrict every service to this requirement for reimbursement services has sometimes been carried to absurd lengths by physical intermediaries.

There is an important reason for a policy of greater flexibility in this requirement. There are times when a short period of illness could be managed effectively in the home, avoiding a hospitalization or in the case of an older person, avoiding a long term institutional admission. If a period of continuous care could be provided during

that illness, a more effective pattern would allow for fluctuation in consumer status and allow the provider and the consumer to decide together what the most useful pattern of care should be.

The part time intermittent pattern works well during periods of convalescence or maintenance, and allowances for periods of special need, particularly for the older consumer, could avoid institutional admission which occurs simply because a week or two of intensive supportive care in the home has not been available. And for a percentage of the admissions that have occurred for this reason, a drastic change in the life circumstances of vulnerable individuals has been the result.

The next important question has to do with, of course, people. What population should home-health services reach? The definitions from the professional fields say people of all ages. Home-health services of good or even adequate quality and range could, in fact, be helpful and useful for people in all age groups, and for people at all economic levels. When the potential target populations are reviewed in terms of the costs of health care, the characteristics in

spending by age groups in the population provide a profile which offers some insight into potential need. About 60 percent of all health care spending in the United States in 1978 was for people in the 19 to 63 age range. This is, the largest age group in the population.

It is also in this age group that threatening childhood disabilities begin to become a handicap, a handicap to fulfillment and social contribution. It is also in the latter ranges of this age group, starting at about age 45, that the first evidences appear of what later become the heavy, individual family and social burden of long term impairment, particularly when these evidences are ignored or untreated.

About 12 percent of the spending for health care occurred in the age group under the age of 19. This population has been decreasing, but it is in this age group that we find the teenage pregnancies, the babies born with low birth weight, the birth defects, and the susceptibility to early childhood disease and disability which are the precursors of impairment and dependency in later life.

Finally, there is the population over the

age of 65. Variouslly labeled "the aging," "the elderly" "the very old" generally seen in stereotypes which include senility, incompetence, depression, dependence, and general uselessness. Stereotypes which are not at all accurate since 80 percent of the people in the old age ranges consider themselves to be in good health and may, even those with multiple health problems, are living satisfying, actively, and productive lives. This group, however, accounted for 29 percent of all health care spending. This is the smallest group in the population, but 43 percent of short term hospital expenditures occurred in this age group.

Next to hospital care, nursing home care was the most expensive health item for persons aged 65 and over. 86 percent of the nursing home population in the United States in 1977 was made up of people 65 and older. If home-health services cannot initially be made available to the population at large and a categorical approach to service delivery remains the only interim choice, what sections of the population are most likely to use home-health services effectively, assuming that the services are flexible, of broad range, and good quality.

Population analysts have identified high risk or vulnerable populations in various ways. Current emphasis is usually placed upon services to that section of the population over 65 labeled in various ways, "the impaired elderly" or the "frail elderly," primarily because of the costs of care which have been thought excessive for this age group.

Another way to look at the population and its needs might be to identify the factors which increase risk and vulnerability. The first of these is poverty. If there did not exist in the United States a population in which more than 16 percent live in poverty, the national health record would be considerably improved and expenditures might be substantially reduced for both short and long term care. The poor at all ages are at greater risk or poor health than the rest of the population. People in poor families are hospitalized more often. They remain in the hospital for longer periods than the non-poor. They lose more work days, more school days, and they experience proportionally far greater disability from chronic disease than the non-poor. Although two million children have been reported as having activity

limitations due to chronic disease, it is interesting to note that a recent home-health utilization study in 1977 in New York State reported that only 1.1 percent of its service population were children.

The second factor includes a range of problems which are very commonly, and I believe mistakenly, consigned to a catch-all category called "social," although it is generally accepted that they have significant effects on health status. These are related to deficiencies in the social support system available to the "at risk" population: Latchkey children in female head of families in which the mother works; untreated teenage health problems; disabled adolescents who have traumatic or long term disability; the chronically ill, middle aged wife or husband with or without children when the presumably healthy spouse is working; and finally that section of the older population in which the destructive combination of poverty and chronic impairment are combined with the absence or limited capacity of family support for care.

In the age group over 65, about 30 percent live alone. Home-health utilization studies indic-

ate that about one-third of the consumers live alone. Most of them, a large number, are women. In these older age ranges when there is family, family members are frequently employed or are entering the vulnerable age ranges themselves and if there are spouses or siblings, they may also be limited in their capacity to provide supportive help because of chronic illness.

We hear a good deal today about concern with -- that one of the dangers of providing home-health services is the danger of drying up the family support system. About 80 percent of the care which is provided today in the United States is, in fact, provided by family members. We are also told by the providers of community services and by some of the hospital discharge planners that one of the frequent factors which precipitates institutional placement is the breakdown in health and in the emotional reserves of family members who have come to the end of their caring capacities through execution, which the provision of supplementary services in the home might have avoided.

The guilt and despair in these families when they are brought to the point of institutionalizing a family member is familiar and depressing to

anyone who has worked with this age group. It would be generally acknowledged, I think, that effective health care measures cannot be limited to care in hospitals, in clinics, in physicians' offices, or in long-term care institutions. These or most of them are measures which usually come into play after something has happened.

We are all hearing a good deal about life-styles these days and about the values of prevention, but while education for changes in life-style have a very real, long range preventive value, there is or there should be something between this ideal and the use of a limited, expensive set of resources. The accumulated effects of intercurrent illness for people who are at risk, whether they are children with diabetes, forty-five year old men who have already acquired heart disease, or 77 years olds with emphysema, do not appear suddenly.

When the incidence of most prevalent chronic diseases are compared across age groups, it is evident that there is no rapid decrease in health status at 65 or any other particular age. The trend is progressive and gradual for adults beginning to be apparent in the 45 to 54 year old

group and continuing steadily up through the 85 plus group.

Those at risk are not confined to any particular age group; in fact, 49 percent of those reporting that are unable to carry on their major activities are under 65. The frail, if that term is to be used, are the disabled population, not necessarily the so called "old," although people in the very old age ranges have somewhat higher rates of disability.

In all age groups, the risk factors of disability are affected by income, by the absence of social supports, and these include, along with such income related factors as bad housing, poor nutrition, inadequate or unavailable preventive and treatment resources, limited or nonavailable effective family support systems. Among the poor, these early precursors of disability are neglected and until they become serious, and then they require urgent measures.

In the older age ranges which have attracted so much attention in recent years because very small percentages of them are accounting for increasing health care costs, they are the neglected problems which have created the concept of alter-

natives.

What have home-health services to do with any of these facts? As they are presently available, the answer is apparent. Very little. If the course and the cost of chronic disease in this country were to be significantly affected by home-health services, a substantial shift in policy would be required. That shift would be based on a recognition of the facts rather than the fiction. The need for an alternative does not arise when an individual is on the point of entering a short stay or long term institution. The alternative to the more costly forms of care does not lie exclusively in education or life-style changes, either.

Between these two, there are a series of effective intervening measures which could be available and many of these, if not all, could be available in accessible, effective home-health services. They might be better insurance against last ditch measures than the measures which are now considered insurance. They could insure against potentially health threatening problems before the threat arrives.

Here another question arises. How can

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effective, accessible home-health services be made available? The general assumption has been that the creation of Medicare for the elderly population and of Medicaid for the sick and poor should have accomplished this objective. That they have not is attributed either to the failure of home-health services to interpret their usefulness or to the indifference of physicians and consumers. Medicare and Medicaid have, in fact, provided a great deal of necessary care to both of the populations for which they were intended.

The emphasis in the planning of the legislation, however, was on the provision of reimbursement for institutional care, because that care was accurately seen as most burdensome economically for these groups. What was not considered was the fact that reimbursement does not build service capacity, particularly when services have not been in place in any substantial amounts for purposes of population and geographic coverage. If there has been overuse of institutional services, some of that overuse, at least, must be attributed to the availability of institutional resources combined with reimbursement for utilization.

In the absence of anything else, the fact that the institution may have not been appropriate for everyone who was admitted was of less importance than the fact that both the beds and the funds were there. On the other hand, home health services have not achieved population coverage or geographic coverage during the period when long term institutional beds increased by 232 percent. There was a reduction in Medicare certified home-health agencies between 1971 and 1974 when Federal policy imposed very rigid constraints on the circumstances in which the services could be reimbursed, and it was only when the shortsightedness of these measures was stressed that a degree of flexibility allowed for the slow growth of the services in the last five years.

It might appear that similar problems have never been confronted before in the United States or involved there. This has not been the case, however. When in the post-war period, there was a Federal recognition that both the scarcity of acute hospital care beds and poor geographic coverage by hospitals was presenting a threat to the health of the population, the Hill-Burton

Act in 1946 and over succeeding years made an adequate supply of short stay hospital beds available.

More recently, interested in health/maintenance organizations through Public Law 93222 in 1973 and in the 1976 amendments, supported recognition of this form of service delivery was funding for health/maintenance organizations for planning and startup costs, feasible grants, planning grants, initial development grants, and loan programs. Last year H.M.O. grant funds were doubled by the Congress and totaled \$48 million.

As a result of this support, this form of service has grown from 39 health maintenance organizations serving 3.5 million people in 1971 to 230 programs serving almost 9 million people, almost 5 percent of the population in 1980.

Home-health services have not received this kind of developmental support. In a five-year period between 1962 and 1967, about 50 short term home care demonstration grants were awarded under the Community Health Services and Facilities Act. No further efforts of capacity building for home-health services were undertaken between 1968 and 1975. In 1975 and in two succeeding years,

\$3 million were budgeted under the Health Revenue Sharing and Health Services Act for demonstration grants lasting 12 to 17 months. These short term grants have been generally considered inadequate for reliable service development.

The legislative conferees noted that the future of home-health services must depend on Federal support of the development and financing of these services. Minimal financing through short term demonstration grants does not make the future of home-health services promising in terms of developing viable and accessible services. The question of cost has dominated every discussion, every legislative consideration, in fact, almost every reference to home-health services for a number of years.

Before the question, How much will it cost, is asked, it might be relevant to ask what the objective in spending the money should be. If it were possible, for example, to provide nursing care at home for a sick, young mother, the services of a well trained paraprofessional for a couple of weeks to avoid hospitalization and the placement of children, that might be a good bargain. If it were possible to provide home-health care

for a 50 year old man with a history of heart disease when he is bedfast with an acute, upper respiratory infection and to monitor his health at home for several months, that might be a good bargain. If it were possible to provide a week or two of intensive home-health care followed by several months of health monitoring to a 75-year-old man or a woman living alone when he or she has an intercurrent illness which might otherwise require hospitalization and transferred to a long-term care institution from the hospital, a frequently traveled path to the long-term care institution, that might be a bargain.

If it were possible to take over the care of an elderly family member for two or three family vacation weeks to avoid or defer a decision for permanent institutionalization, that might be a good bargain. And if, for a relatively small percentage of the population, particularly those in the older age ranges who are at risk for institutional admission, if it were possible to confront the fact that a few hours of paraprofessional service and an occasional visit by a professional would be needed indefinitely, that might prevent or delay for that period of time a more costly

choice, that might also be a very good bargain.

It is probable that what is being provided at present is not a good bargain at all. To wait for the time when the need, whether it is medical, social, or custodial, has arisen, and then to make fourth decision, and fourth choices, seems on the contrary to be very expensive as most unplanned events are apt to be. In this context, if some of us are asked whether we are advising our planners and policy makers to buy a "pig in a poke," the unavoidable reply is that in all probability, that purchase has already been made without advice.

There are few hopes that so called "cost control measures" without some alteration in the service system will achieve their objective. The demonstrations and research efforts directed to the costing of home-health services as they are presently delivered, simply describe what we have and what we have is an absence in a set of services for the population that is that object of cost control. What we have are services that do not provide the right mix and are delivered more or less for the wrong reasons. They are not matched in service pattern or in duration to consumer need.

This combination is not going to produce any information except a record of the costs of something we have concluded as not very effective. This, however, is not the cost question that is considered relevant today. The most frequently asked questions arise when support for effective home-health services systems are considered is what will it cost in dollars and cents? And the subsequent questions are: Will it save institutional days? Will it be cheaper than institutional care? How many days will it save? And finally, will it be an add-on cost?

There have been a number of efforts to answer these questions. Some of them have come from Congressional reports. A Congressional report in 1972 estimated that if one day of hospital care for one patient in 20 could be served with available home-health care, a total of \$100 billion in savings would be realized. Blue Cross of Greater Philadelphia reported that with home-health care over a period of nine years, nearly seven additional hospital beds were freed at no additional cost to the community.

The Congressional budget office in 1977 referred to this evidence on cost stressing the

fact that the cost studies referred to hospital care. It cited a study indicating that 85 of 245 patients, presumably candidates for long-term institutional care, were maintained on continuing home care and would have required institutional care if home care had not been made available. Twenty five of the patients would have died. Over a period of 24 months, 23 patients improved to the point that they were no longer home bound, and 116 remained stabilized under the program's continuing care.

The Congressional Budget Office report suggested that a long-term care system would be necessary in view of the projected increases in the aging population and proposed several different options for long-term care service systems, all of them involving a wide range of home based services. The fact remains, however, that the best basis for costing the service would be experience with an extensive home-health services system, one that had, in fact, dealt with the population in need of long-term care.

We have not had this experience in the United States. The home-health services from which any existing data might be drawn have usually limited

their services to a maximum of 90 days or to the 15 limitations which Medicare regulations impose, except for a minimal experience with consumers who are able to finance the care from their own funds.

Aside from the fact that there is no assurance that any of the research on cost is reliable, a question arises again, Are we attempting to cause a result or are we looking for a way to control the causes of the expenditure? The best way to control the costs of long-term care and to some extent, acute care as well, would obviously be to avoid the excess morbidity that necessitates that expenditure. This might be achieved through home-health measures of preventive intervention.

Some of us believe that this would not be too costly and while it might not immediately show economies and the utilization of institutional beds, it would do just that in the long run. As a matter of fact, for the long term consumer, this preventive approach to impairment over time if the initial effort to develop sources could be achieved might require far less in the way of services and achieve far more in the way of results, than we can

assume from the studies now in the field.

The word "preventive," which usually seems to describe something non-medical and therefore not the business of health establishment, is meant here to mean that services are delivered exactly when they are needed in order to control and prevent the development of problems that are preventable. This means service delivery before the institutional choice ever appears as a possibility. Home-health services are a key element in long-term care. They are both a health service and a supportive service. They must be linked in the system if it is to be effective.

In the face of much of this rather disconcerting evidence, we continue to hear the same statements about home-health services that taking care of sick people, particularly older people in their homes, is humane because they are happier there; that home care is preferable to institutional care because older people do not adapt well to institutions; that taking care of people in their own homes preserves and maximizes the contributions of informal care; that home-health services are an alternative to institutional care; that providing the services would prevent

people being institutionalized inappropriately; that home-health care would prove to be cheaper than institutional care.

Like all arbitrary statements, these should be taken with a grain of salt, but if they are even partially true, they should again be followed by a series of commonplace questions. Why have home-health services been so minimally utilized? Why have the development of home-health resources been so slow and so disappointing? Why has there been so limited an attempt to get at the question of cost if cost comparisons are, in fact, relevant to the need for care at home as compared with the institution?

Here we have the questions that have been presumed to be central to the issue of home-health services and their value, and we have some partial answers. We know that there is a population in need of long-term care. We know that this population has multiple problems and that the present situation is threatening to a growing population and threatening to a system of management based on last ditch efforts.

We know that neither Medicare nor Medicaid home-health services have provided care that fits

the needs of the most vulnerable population. We know that some experience with home-health services have demonstrated that they have effectively avoided institutional care and even replaced it.

They are not an alternative. They may, however, be a more appropriate way of caring for a sizable number of people. We know that no resource which must provide a set of professional and paraprofessional services for a population without the means to buy them can be self-generating and that no such service complex can survive on reimbursement alone. We know that physicians and discharge planners and care planners cannot be expected to be enthusiastic about the use of a set of services which either are not available, are inaccessible, or are so restricted that they cannot be used with any great degree of confidence, particularly over the long term.

We know that efforts to develop home-health service resources has been in the face of the estimated need so minimal as to make no difference. We know that research based on present efforts is unreliable because the base in which it is being undertaken cannot provide an accurate point of departure.

A formidable barrier exists in the legislative structure on which home-health services are based. Funds for service reimbursement must be sought from a dozen or more sources. I think at one point we figured 18. Public programs deliver from one another in their eligibility requirements, in the services they provide, in the definitions of those services, and in Federal, State, local matching arrangements.

There has been very little standardization in the claims' review process. What is reimbursable in one locale may be rejected in another.

The insecurity that this fragmentation engenders adds to the problem of the consumer, the planner, and the provider. The consumer, of course, is the ultimate sufferer in this fragmented and uncoordinated system. The costs are human, but they are also costs in practical terms, and however willing the general public may be to support its vulnerable populations, the disarray in the arrangements for such support is less than encouraging.

The key question, What is to be done? There may be several answers. Years ago Franz Goldman,

the father of theory and home-health care, said that effective services begin with sincerity of intent. He called it the will to do and while this may sound somewhat naive in view of much of the cynicism that is prevalent today, it would be difficult to find a substitute for the action that follows from a determination to achieve an objective which is essential to the public.

Following from this determination, the formulation of public policy and the steps which implement such a statement of intent are essential. These involve the placement of responsibility in an identifiable and accessible public unit which will begin the task of unifying definitions, standardizing measures of quality, reconciling the disparity in program differences, vis a vis the target population and their eligibility, bringing some order into the morales of Federal-state-local managing arrangements, reimbursement policies, and claims' review. It will mean a somewhat longer range, but coordinated and planned approach to the development of accessible resources. One of the most important elements in such a program will be the influence in this system of rational arrangements for noninstitutional care of the population now in

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need of the long-term care. This latter approach may be the single most important element in long term cost control. None of these efforts can be let to chance or to good intentions. These steps are long overdue and we will continue to ignore them at great risk.

Thank you.

MR. SPECTOR: Thank you, Brahna, for your very thoughtful and challenging remarks. The rest of the day, I think, and indeed the rest of the year and the future has been challenged here and we hope that we'll be able to deal with it.

At this time we would like to take a break. There will be coffee outside. I would ask that when we resume, the panelists for this morning's session please take your places at the front. We know who you are, you know who you are.

See you in 15 minutes.

(There is a recess.)

MR. SPECTOR: I would like at this time to introduce this morning's panelists. The way this will go for the intent purpose of the program is we'll ask the panelists to speak. We would ask that you would hold your questions if you have some, perhaps write them down, until the end of the

panel discussion and from the time that they finish until the time we must adjourn for lunch, and I will announce that at the end of the question/answer discussion, you will have some time for some response to the panel.

Brahna Trager will be here for the remainder of the day and we did not give time for questions and answers, but I'm sure, she told me she would be more than happy to respond to your questions if you have any throughout the day.

For the benefit of the stenographer and for ease of identification, I'm going to introduce the panelists, not necessarily in the order they will be speaking, but rather from my far right to my far left.

On my very far right we have Dr. Leighton Cluff. Dr. Cluff is a medical doctor and he is presently the executive vice president of the Robert Wood Johnson Foundation. Previous to that he was Professor of Medicine at John Hopkins University and held a similar position at the University of Florida.

To my immediate right, Martha Darling, who is the legislative assistant to Senator Bradley. Her primary responsibilities include the Committee

on Finance and Aging of which Senator Bradley is a member. Martha came to Washington as a White House Fellow in 1977 and worked in the Department of the Treasury as Executive Assistant to Mr. Blumenthal.

To my immediate left we have Rita DeCotiis. Rita is the Executive Director of Nursing Services Incorporated and is currently president of the Home-Health Assembly of New Jersey, Incorporated.

Farther on to my left we have Ron Muzyk and Ron is the Acting Chief of the Bureau of Program Development for the New Jersey Division on Aging, Department of Community Affairs. He is also a staff member to a long term planning committee for the State Channeling Grant which you will be hearing from more about today, and he is on the interagency task force on home care services.

And to my very far left is Gerald Reilly. Mr. Reilly is the deputy director of the Department of Human Services and prior to that, he was the director of the New Jersey Medicaid Program and my former boss.

First speaking this morning will be Rita DeCotiis.

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MS. DECOTIIS: Thank you. First I'd like to say, what do you do when you're the speaker on home-care after someone like Brahma Trager? Kind of leaves you speechless, doesn't it?

As president of the Home-Health Agency Assembly of New Jersey, I would like to express our sincere appreciation to Governor Byrne, Senator Bradley, and Senator Williams for their cooperation and co-sponsorship of this meeting today. I would also like to say that the committee who was listed on the back of the program has worked close to a year on planning this conference. Let's all give them a little thanks.

Some of the things that I'm going to say are going to be a little bit repetitious of what Brahma has brought to you already, but I think they bear repetition. I'm addressing you today as a spokesman for the Home-Health Agency Assembly of New Jersey, which represents the 47 certified licensed home-health agencies in the State. These agencies are a mixture of non-profit voluntary hospital based, public health department based, and one proprietary, and they provide services in the home that include nursing, physical therapy, occupational therapy, speech pathology, mental

health, medical social work, nutrition counseling, and home-health aides, all provided under a physician's plan of treatment.

In 1979, 41,000 patients in New Jersey were served. In the past few years, home-health agencies have become increasingly involved in hospice programs providing the skill, professional care, and support services necessary to allow the terminally ill patient to die in dignity in their home.

The traditional eight - five home-health agency day is becoming a thing of the past with many facilities now providing care seven days a week, 24 hours of the day. I can remember back when I came back into public health. It was a darned good job to have because it was Monday to Friday and once in a while a weekend call, but nothing more than that and it was from eight to four. This is changing. Care of the acutely, chronically and terminally ill in the home is not, however, our only role.

Home-health agency health conferences provide nursing to private schools, offer health consultation, educational and screening programs in the community, and in many areas, act as the

local Board of Health Nurses. We help the local Board of Health meet some of their mandated standards. Home-health agencies are the only health facilities today that can boast of such a wide variety of involvement in health care in the home and in community health.

We are deeply concerned with three basic issues in the delivery of home-health as it exists today under current legislation and is proposed under pending legislation. The first issue that we would like to speak to is coordination. You're going to hear this over and over again today. Title XVIII, Medicare; Title XIX, Medicaid; Title XX, Social Services; and Title III, the Older Americans Act. All provide for some aspects of health care in the community. Each have different eligibility criteria, different definitions of many services, and different modes of entry into the system.

Health services provided by Medicare and Medicaid are basically under the supervision of the Home-Health Agencies, but in many areas of the State, there is little or no coordination of these services with those provided by Title XX. It is not unusual, the care of a patient to be paid by

three or more funding services. I think Brahma said 18.

Title XX may be supplying health care to the patient with different personnel, often unsupervised, and with no communication with the home-health agency. It is not unusual for us who are directly involved in the provision of care to go into a home, to be having a home-health day there, and discover two or three weeks later that Title XX also is providing a certain number of hours of care to this same patient. This is certainly not good coordination of care.

It is essential in order to provide quality home-health care that there be coordination of all services and that there be a single point of entry into the system. Channeling demonstrations, which you will hear about later today, may show the way to such a coordinated system.

Our greatest concern regarding channeling demonstrations is that agencies involved be the most qualified to coordinate a program that will have such an impact on the delivery of home-health care. We believe that home-health agencies are one of the logical choices for a demonstration project or should be deeply involved in the dem-

onstration project.

The second issue is one that we are sure you all are aware of, but feel we must, again, restate our problems with cap law as it exists today. Cap law limits any increase in municipal and "can't be" expenditures to 5 percent presents a definite hardship for our public-based agencies. These agencies are primarily reimbursed by Medicare, Medicaid, Blue Cross, and private insurance companies, yet because of the cap law, when there is a need for expansion to provide home-health care, they're unable to, due to constraints of this law.

Needed nurses or other professional staff cannot be hired even though the personnel costs would be reimbursed by fiscal intermediaries. We strong recommend that this construction on the publicly based agencies be removed and that they be exempt from the cap law to allow them to expand to meet existing and projected needs.

The last issue we would like to comment on is funding for home-health care, its fragmentation and inequities as compared with other health facilities. I think Brahma kind of touched on this, the Hill-Burton Act. As was said earlier, it's not

unusual for home-health agencies to have on their census a patient who may be receiving services under three or more separate funding sources to achieve a level of care that is skill inadequate.

As of now, Federal programs have not provided the funding that would allow the type and duration of services needed to render comprehensive, long-term health care in the community. Home-health agencies have been forced because of funding restrictions to place greater emphasis on short term care.

The Medicaid program in New Jersey, I would like to say, although one of the most comprehensive and best-planned programs in the country to assist in keeping the extreme poverty out of institutions has such a low financial eligibility for home-health that only 7,000 people in New Jersey can benefit from this. The Medicaid community health cab interview by Waxman and Pepper would help to alleviate this by raising the availability of home-health care so that it would be comparable to nursing home eligibility and Medicaid.

Yesterday I heard two different figures and I don't know which is right, but there is just about a \$500 gap between the Medicare eligibility

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for home-health care and Medicare eligibility for nursing home care.

Title XXI which is the most comprehensive, long-term care legislation as opposed to short term care funded by Medicare to date calls for initial screenings and referral operations, but does not really delegate where these will take place. Further, it delegates as those eligible to perform this preadmission testing of facilities such as a nursing home, which has never demonstrated expertise in this area. This could only result in filling nursing home beds.

We firmly believe that the point of entry to any long-term health system regardless of the funding source should be through a certified licensed home-health agency. In view of our history and experience in patient assessment, referral, and provision of care, this would certainly lead to better coordination and less duplication and fragmentation of services. Lack of expertise in the aforementioned areas can only result in inappropriate referrals to nursing homes.

We are all aware of its existence today. Senator Bradley touched on it with those who are in nursing homes, who do not belong there. But I'd like

to say something else.

It could also lead to inappropriate referrals to home-care. We who work with it every day have a frustration of how to safely care for the severely, physically, mentally limited person living alone in a totally unsafe environment. We have had little support from the private sector of insurance. Many health insurance policies will pay for private duty of registered nurses or licensed practical nurses, but will not pay for the services of a certified home-health aide working under the supervision of a public health nurse.

Too often patients who receive reimbursement for their post-hospital care are forced to engage registered nurses in the home rather than the more appropriate and cost effective use of the home-health agency services.

The dollars spent in 1979 by the private insurance companies for home-health care only amounted to 1.3 percent of our total reimbursement for home-health. Now, I think that's kind of a standard. Nonprofit voluntary health agencies are mandated by their charters to provide patient care regardless of ability to pay.

It states it right up there in black and

white; however, few agencies are fully able to live up to this commitment due to financial restrictions. Funding from private sectors such as United Way is not usually sufficient to meet the needs.

Federal programs such as Medicare do not allow the agencies to accrue any reserves and in the past few years, there has been only a few million dollars of Federal funding, I think Brahma said three, for the whole country that was available for home-health expansion.

Now, this is the whole country. This is not New Jersey. Over the years, hospitals have received Federal financial support for expansion, but very little assistance has been given to home-health agencies. The problem in providing long-term care is even more serious. If we are to expand to provide services, we must have the funding to enable us to hire the highly skilled professional and paraprofessional staff needed at salaries that would be equitable with their responsibilities and their responsibilities out in that community are really tremendous.

With the constraints of the existing reimbursement methods and the limited Federal financial

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assistance, we ask you, the policy makers, how are we to expand over and above the 20 percent annual growth rate that we are already experiencing in New Jersey? The need for long term home-health care as a more appropriate form of care than institutionalization is there, and we are confident that we can provide that quality home-health care given the backing of effective legislation and sufficient funding.

Thank you.

MR. SPECTOR: Next I would ask Dr. Cluff to speak.

DR. CLUFF: Thank you. It's a pleasure to have the opportunity to be here with you today representing the Robert Wood Johnson Foundation, which, as many of you know, has over the past eight years been very intensely interested and has committed its efforts to improvements and access to our hospital general medical care.

The Foundation up to this time has not specifically supported programs dealing exclusively with home care, but it is an area of over-riding interest to us. This conference today is an obvious interest to those of us who represent the Foundation.

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My comments will be a bit extemporaneous and I have a few specific points that I would like to make, which hopefully will precipitate some discussion and perhaps might even be a bit provocative.

As we have over the past 18 months or so attempted to try to look into the crystal ball of the future in health care in this country, it has, of course, come to our attention, as I'm sure that you're aware of as well, and that is that during the 1960's and the early part of the 1970's, of course, there was an extraordinary expansion in the availability of public dollars and public programs for provision of services of all kinds and particularly in the field of health services. We recognize, as I'm sure you do as well, that during the decade of the 1980's, the rate of growth in the addition of funds for support of such services will be obviously much less than it has been in the past.

Various projections would indicate the rate will slow at least in terms of growth of new health services and the support of existing health services by perhaps one half.

In addition to that, we recognize also that there is a growing concern in this country regarding the whole issue of, if you will, productivity and

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certainly in the area of health care with the whole issue of cost effectiveness, that phrase being exceedingly difficult to define in the health care field; however, as one looks at the issue of the cost of health services as all of you know, the cost of health services have risen in an astronomical rate in this country in the past 15 to 20 years. Now, part of the issue here is clearly also associated with the problem of disability or functional impairment with our population. There were some 452 million work days lost in 1979 in this country because of people being disabled acutely, temporarily, or over a long term because of disabling health conditions. Indeed, that exceeded by 12 fold, the work days lost attributable to strikes in this country.

Indeed, it has been estimated that private, state, and Federal dollars contributed is somewhere in the neighborhood of \$342 billion in 1979 to provide health, economic, social, and support services to the disabled people in this country. That represents as rather clearly to you as it does to me a rather considerable expenditure of funds in this country and commitment to meeting the needs of our disabled people.

In that regard I'm using the word "disabling" or "disability" in its broadest contexture framework.

Now, in regards to the issue of home care, one of the questions, of course, that needs to be asked and has been asked this morning by Dr. Trager and by others, and that is who needs home care and how do you decide who needs home care? Indeed, you who are the providers of home care services can answer that far more precisely than I can, but certainly one thing I think was raised earlier, and that is that indeed, home care is not a problem that is exclusively confined to the older population or the elderly population of the country, even though at the present time it has also been pointed out that it consumes the largest proportion of the dollar of sources in this country for all health services, at least as a single population group.

Certainly, therefore, we can claim that most of those with activity limitations, even those with major limitations, still are under the age of 65, but the cost of the health care services goes over that age.

Now, another question in terms of who needs

home care deals with the whole issue of the assessment of the need of individuals. I was interested in talking to some of you this morning that, indeed, there appears to still be some differences of opinion perhaps and certainly different forms being used to identify those in need, the level of their need, and the types of services that are required. Indeed, it's been our feeling that perhaps this in one of the weaknesses of home care services and other kinds of services at the moment, and that is how does one characterize the functional disability of those who are at home or could be at home and how does one based on functional assessment identify the need? I'll come back to that again in a moment.

Now, one of the important questions Senator Bradley addressed and so did the Governor, and that is does home care cost less than institutional care? In this regard, clearly we're primarily talking about the nursing home. Now, as has been mentioned, there have been some studies done to try to examine this issue. For example, one study done entitled "Home Care for the Elderly in North Carolina," a program titled "The Client Centered

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Coordinative Program." Indeed, an effort was made to try to examine this issue, but one great void in providing services for this population was a method for bringing together all of the appropriate services to meet the individual's need and, indeed, this gets back to Rita's point about the need for coordination of services.

They used in that program a surrogate method in order to try to coordinate the services needed by the elderly population at home and indeed to not only identify the need but to seek out the services that the client required.

It was interesting to note that 60 percent of those they served required no special nursing attention, nor did they require any special medical services and that the cost of the rest of the care in a rest home for those individuals not in a nursing home comparatively was of \$400 as opposed to the cost of the home care program being \$410. It was recognized that 30 percent of the population that they served required limited nursing or medical services and that the cost of an intensive care facility for this population would have been amounted to \$880 and the cost of home care was \$474. Only 8 percent of the population required

extensive special nursing care or medical services and as we will know in this instance, the cost of the nursing home care averaged \$1190 per annum and \$581 for home care.

Now, it's this kind of study that is critically needed if one wants to demonstrate what has been pointed out earlier, and that is that home care basically is capable of reducing cost and total care. In this particular study, one can claim that it did for certain selected portions of the population. In a program sponsored by the Robert Wood Johnson Foundation, the program known as our Health Impaired Elderly Program in ten demonstration sites in ten states throughout the country, one of the things we've been trying to pay attention to are two things.

One is the appropriate coordination of existing community resources. Is it possible to reduce the need for institutional care and indeed is the functional effectiveness that the population served improved? Hopefully we'll be able to obtain some information regarding that in those ten demonstration sites over the next four years. Again, however, it's this type of study that we feel is absolutely essential if one is going to

be able to justify the continued expansion of home care services.

One of the important studies that has been done, to my knowledge, is now being used by the United States Congress in assessing the whole issue of home care and that is the so-called "Weisser Study." It was reported in 1979 and I'm sure all of you are aware of it.

Indeed, the cost effectiveness of day care and homemaker services for the chronically ill was done in a randomized study reported and supported by the National Center for Health Services Research. Three critical findings in that study are having major impacts on national legislation. That study reported that they found that the cost of home care was more costly than day care services. Their findings suggested that day care may not be cheaper than nursing home care, and they did not show that homemaker services constituted a cost effective alternative to long-term care.

Now, that study is currently having profound impacts in Washington on the whole issue of legislation regarding home care and perhaps Miss Darling will speak to this later on. It's this kind of study which contradicts many of the

things you believe you're doing, which are so important. The study had great weaknesses, however.

It was conducted over a two-year period of time. The data was collected only about over an 18-month period of time and it is difficult to know whether such a short term study is adequate to effect the whole of home care services when one is providing long-term care.

There is an interesting study being conducted at the Johns Hopkins Hospital and the Massachusetts General Hospital, programs coordinated by those two institutions for home-health care. A certain proportion of those individuals being discharged from those hospitals who are deemed to be requiring nursing home care by their physicians are being randomized into two groups and, indeed, one group is being assigned to a nursing home, another comparative group is being assigned to a surrogate or foster home program.

As I'm sure you're all aware, many elderly people and chronically ill people being discharged from the hospital do not have a home to go to where there are individuals and residents who can provide their care and, indeed, many studies suggest that's an important reason why some people

are admitted to nursing homes, not because they necessarily need the nursing home, but because there is nobody at home to provide for their care, so these two hospitals basically have developed programs for care given in which the hospital staff assumes the responsibility to train them in providing home care services for the individual discharged from the hospital who resides in the home of the care giver for a period of time until they can assume more independent living again.

The data from that study up to this point in time suggests that the cost is less for the home care services or in the surrogate patient care giver's home than it would be in the nursing home on a per diem basis, but one of the interesting things is, and I would wonder if you haven't observed this yourself, some of those patients actually live longer and therefore if one looks at the total cost of care, the total cost of care is greater. But it's this kind of data that one has to pay attention to.

The issue really may not lie in cost but what is best for the individual to be cared for or live at home or reside in a nursing home.

Now, if one is really doing a comparison with nursing home care which is certainly the big issue in regards to the elderly, I'll just recite briefly some data which clearly emphasizes the magnitude of this issue. In 1970 there were \$4.3 billion spent for nursing home care in this country and in 1980, it's estimated this will be a \$23 billion expenditure and this is an 18 percent compounded average increase.

Indeed, if the cost per nursing home bed is assessed, the cost for a nursing home bed in 1970 in the country was \$4,300 per year, and in 1980 it's estimated to range at \$13,450 per year, a twelve percent compounded average increase.

During this same period as you all know, there were one million nursing home beds in the United States in 1970, some 1.7 million in 1980. It is important to note in terms of cost that the national study indicates that 75 percent of all Medicaid dollars in the United States are currently committed to supporting patients who are in nursing homes. That doesn't leave much money for support of home care services.

What about the population of the elderly which have such profound impacts upon the whole

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situation, and I don't need to go over this with you except to point out one very important thing and that is that the population between the ages of 65 and 74 is expected to decrease between now and the year 2000 while the population over between the ages of 75 and 84 will rise from 34 to 44 percent and that will be an increasing proportion of those over 85 years of age rising from 5.6 percent to 10.5 percent.

If we think we have a problem now with the disabled and the functionally impaired elderly, it behooves us to think clearly about what the problem will be like in 20 years. It has been mentioned before by Dr. Trager that, indeed, the majority of the patients, 86 percent of those in nursing homes are over the age of 65, but it is critically important to recognize that 70 percent of nursing home residents who over the age of 70 and that, indeed, one-third of the patients in nursing homes today are over the age of 85.

Now, 75 percent as Dr. Trager pointed out of those in nursing homes are women, and this presents a problem which, I think, is of critical importance and 88 percent of them are single, divorced, or widowed. So basically the family

structure has changed dramatically for this population.

One thing that struck me is why people are admitted to nursing homes. In the 1977 study by the National Center for Health Statistics, one-third of those individuals admitted in nursing homes in the United States are not admitted because of what I can get from the data represent medical or health problems, but are admitted because of social or economic reasons. Now, it is also important to point out that of those who are admitted to nursing homes and pay their own bills or have private insurance, do not have Medicaid, that about 40 percent of them will be discharged from the nursing home within three months but of those who are admitted to a nursing home under Medicaid, the average duration of occupancy in the nursing home is one year-and-a-half.

In part that's attributable to the fact that the individual in the nursing home on Medicaid becomes entirely dependent on those Medicaid funds for their support, yet if they leave the nursing home, the level of their support is not adequate to provide for their care.

Now, these are some of the data that I have

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attempted to examine in dealing with interests of this particular conference, and let me just identify some of the kinds of questions which have already been raised, but which I think need very serious attention.

What are the means of payment for services for individuals who require home care and/or the kind of resources available adequate if they were more appropriately deployed? I think that's a critical question for all to ask, are the existing resources available for home care services adequate if they were more appropriately deployed?

Clearly this would require some additional coordination of services, a better means of assessing the means of those who require home care services, and I have a great concern that any program dealing with the home care of the disabled population, particularly the elderly, should not be a program that drives out volunteerism. Volunteerism is a big part of home care services at the present time, and from my own vantage point, the activities of the Ohio Presbyterian Church and the Baptist Convention of North Carolina represent the kinds of voluntary efforts that can make an

immense contribution to the home care needs of the elderly and, indeed, we have to be very careful that as we develop expanded reimbursement mechanisms to provide care for these people at home, we don't drive out volunteerism.

In this regard, I happen to believe that there's a crying need for an increased degree of cooperation between private and public sectors. I don't believe that the home care disabled persons should be exclusively and totally a public responsibility. I happen to believe that a cooperative arrangement between the private voluntary sector as well as the public sector is badly needed.

Finally, one of the missing ingredients in nursing home care from my perception of some of the programs dealing with home care is their lack of an effective linkage to the rest of the health care system. Indeed, it seems to me as though it is time we began to think not about home care, period, but about the total care of an individual who is disabled which may require involvement of the physician, hospitalization, nursing home care, and home care. Somehow or other these have to be linked and they cannot each

individually be considered in isolation of the other.

If I were an old person, such as my mother, who's 91, has a paralyzed right foot, has two artificial prostheses, is partially blind, partially deaf, but alert, and lives at home alone and cares for herself alone. What she needs is a little bit of home care periodically. What she needs occasionally is hospitalization. What she also needs occasionally is to see a doctor. And what she also needs sometimes is to see a podiatrist.

So that in essence it would be inappropriate to talk about the needs of my mother as being exclusively these for home care. Somehow her care has to be linked into the rest of the health care system and I think it's absolutely critical that when one talks about home care services, one put it in the context of the total health care system and the needs of the individual which will vary from point to point and time to time.

Thank you very much.

MR. SPECTOR: Thank you. I now ask Ron Muzyk to speak.

MR. MUZYK: Good morning. As I was sitting listening to Brahna Trager, Rita, and, of course, Senator Bradley and Governor Byrne, I was thinking back to somewhere around the neighborhood of two years ago when several of us at the State level began to talk about long-term care, long term planning, and in-home health services. Out of that came our first effort about a year ago which we called the 1923 Conference. Some of you were there.

It brought together for the first time three very, very, I would say, powerful funding and resource agencies in this State, Title XIX, Title XX, Title XXI State and area agencies on aging to bring them together, to develop some sort of working relationship with each other to help foster transportation in home services, energy management, et cetera. And from that I think we can see today that the transportation needs through the Governor's task on transportation of the elderly and handicapped and the 1923 Conference we are seeing transportation being coordinated at the county level like we've never seen before. We've brought it together.

One of the other seminars or workshops of

this 1923 Conference was on in-home health services. We brought together many, many leaders from the State Federal government to talk about it, and I think what we're seeing here today is a result of that long process, having the voluntary sector of the State all coming together to discuss things that are very, very important.

When we began to look at the Division of Aging and the Aging Network out there, we see sort of a dichotomy or some sort of other mechanism that on the one hand they tell us to do things and work with people in other agencies, and on the other hand they mandate that we provide services. So when they passed the most recent Older Americans Act Amendment, they set forth that in a certain portion called "social services" the area agencies in the State must certify that 50 percent of those funds be used to provide three basic services, access, in-home services, and legal services.

Yet inherent in those amendments was the fact we had to pick up certain other services previously being provided by the nutrition program so we saw we were picking up nonin-home services, but after a small while, we see the

pendulum swinging, through the 1923 Conference, the Governor's Conference on Transportation, our agencies have moved and are moving very rapidly out of the transportation business. They are finding other resources to provide that and the pendulum is being swung into the area of in-home services.

Those of you who were here last night saw the film "Visiting Nurse and Health Services of Elizabeth, New Jersey," one of our first programs we started on the Division of Aging and if you look at each and every county in New Jersey, some element of that program if not all is being provided through the area agencies, through other providers in almost every county, so our pendulum is swinging and we are beginning to divert more and more funds into the in-home services area.

The other program that my director Mr. Pennestri, who would have been here today except that he is in San Diego at the Gerontological Society talking and giving a presentation on congregate services, wanted me to talk about is the program we started here in the State, and I'll get back to this in just a moment.

As we said, with the Visiting Nurse Assoc-

lation and the health services of Elizabeth, we have semblance of programs. One of the things that our director, Mr. Pennestri, feels is very important and will be coming up in the new amendments to the Older Americans Act which is to begin to see new titles in the Older Americans Act which may deal with in-home health services in one way, shape, or form.

Either through the Channeling mechanism or through the Robert Wood Johnson Foundation's health impaired programs, we will see more and more funds perhaps going through the Older Americans Act for in-home services.

One thing you'll see changing is through the White House Conference on Aging and the Governor's Conference is that you'll see much more impact on that long term planning in the home-health services program because as we see, as we begin to code all of the form reports and meet with all the members of the task force and begin codifying this for the delegates, we are seeing that in-home health services and long-term care planning is a very, very important element. It is coming up and it is servicing, so our delegates will then take it out to Washington. I think

through the whole nation you see things happening.

Out in San Diego, my director, Mr. Pennestri is presenting a paper along with several other staff members on congregate services. We at the Division on Aging look at this as being one more way of delivering necessary health and social programs to the elderly. Congregate services began about a year ago. We have seven projects out there presently.

It provides some personal services, some homemaker services, and nutrition and we're exploring ways to make it more enriched by adding elements of home-health such as visiting nurses, home-health aides, et cetera. We hope to do this soon.

Through other programs we have been placing older workers themselves in programs we call "residential housing aides" to pick up the light house duties, the chores, the letter writing, the other non-medical services, to the elderly within nine projects in the State of New Jersey. That's working out very well and we're beginning to go into a few more projects come this July.

When Jim Pennestri, our director, is talking and doing things, he comes back to always

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our first director, Mrs. Harter, who, back in 1965 when the Older Americans Act came through, she went for planning and coordination rather than for direct service development. She created the county office on aging.

From about that time to 1972, we actually got out there and planned and coordinated, pooled, and capped and uncapped resources from more of the providers there. Then came money. It began slowly, began to build and build. We sort of lost sight of the original concept that we, the area agencies, are advocates for change for the elderly to include them in the regular service channels and add on our behalf for change, so therefore now that the Older Americans Act came completely around and all of our funds are going out now through the area agencies to service providers for all the things, we have a better chance to begin to look at this problem of in-home health services and long term planning in a more concentrated manner. In our own Division as Dr. Cluff mentioned today, we are working with the religious community to develop in-home services and other services through the religious communities in New Jersey.

We are also working with the housing authorities again on the congregate services program. We are educating and training people in the field to be alert to the problems and needs and services of the elderly person. We are also working with what Governor Byrne alluded to this morning, constituencies.

For the first time in a long time, the Commission on Aging and the members of key senior organizations have come together to plan strategy to meet the needs of the older persons in New Jersey. What we're working on is bringing everyone together for common good and that is to provide perhaps better in-home health services and other services that the elderly in New Jersey need and require. When you look at what will be happening, perhaps it can be authorization to the Older Americans Act and what has happened just recently, we sort of feel that we can backtrack on the aging Americans.

We must look at and reorder our priorities. As I said before, from the community performance which you've held our priority is beginning to come about, and that is for in-home health services. We as a Division on Aging, working with the other

divisions in the Department of Health, the Department of Human Services, will begin working more and more together to make sure that our constituency, the elderly, is included in all home-health services and pledge our support to carry out a much bigger and better program if humanly possible to meet those needs and to keep individuals from being prematurely institutionalized but at the same time allowing those who are institutionalized to come back into the community.

And we hope that the Older Americans Act, our Congregate Services Program or Residential Aides Program will be able to address this more and more in the coming years.

Thank you very much.

MR. SPECTOR: Thank you, Ron. At this time I would like to ask Gerry Reilly to give his presentation.

MR. REILLY: I want to touch upon four areas. The time is too brief to touch upon all of them in sufficient detail, but they're all important and I do want to mention them.

I want to talk about recent policy initiatives I want to talk about barriers to service. I want

to talk about current policy developments. I want to talk about some long term views and projects. Two key policy initiatives undertaken in the past several years that are already substantially accomplished involve first Medicaid coverage for home-health services which Rita alluded to a little bit earlier. It used to be that in order to get help from the Medical Assistance Program or Medicaid, one had to be sick enough to be in the hospital in order to get home-health care, somewhat of an anomalous situation which parallels the Medicare principles.

We changed that several years ago and developed a level of care approach which involved an intense level, skilled level, and basic level of care. The results of that change in policy are rather significant in terms of expenditures and people served.

In 1976 the New Jersey Medical Assistance Program spent about \$2 million on home-health care. By 1980 that number had jumped to \$9 million, an increase of 356 percent.

In 1976 we spent three-tenths of one percent for home-health services. By 1980 it had jumped to a magnificent 1.4 percent, a 366 percent

increase, a small total portion of the budget obviously but a rather important trend and shift.

In terms of people, 1976, about 570 people per month, by 1980 about 1200 per month.

Second major area of policy change already accomplished has been the shift from the Title XX program to the Title XIX program where appropriate and possible. As you know, many county agencies with the use of Title XX funds conduct homemaker home-health aide programs in the state. A number of these people receiving help under the home-health aide portion of Title XX program were also eligible for XIX but were not being paid for out of XIX. The Title XX funds of New Jersey are capped.

There's a Federal cap. I suppose at that time it was 2.5 billion. It moves up and down with various appropriations, but essentially it's capped so that the advantage was in moving services out of Title XX which was capped into Title XIX which was uncapped, thereby free and Title XX served funds for additional services for people who Title XIX could not assist, and that has been underway in most counties of the State and is working fairly well, I believe.

Nonetheless, because of the tremendous and continuing increase in demand for services in 17 of 21 counties, we now have restricted or closed intake for county-sponsored Title XX and county-assisted homemaker health services, so that the Title XIX switch, as it's called, in the trade was helpful for a few years, but now that particular trick has been bled dry and is not enabling us to respond to the current needs.

The barriers of the further progress, obviously No. 1 is money. Number 2 is eligibility. Rita referred to the institutional cap. What that means is if a person lives in the community, they have to have income of \$238 or less per month to be eligible for supplemental security income payment. If that person is in an institution, the cap is three times that rate, about \$717 -- 714 per month, about a \$470, 500 difference.

Now, the intent of that regulation is benign. It is to assist people in meeting the crushing cost of institutional care if, in fact, they require it. Its impact in certain circumstances could be perverse because an individual who was in a long-term care facility conceivably

doing well enough for reintegration into the community may face the prospects of losing their medical assistance benefits on re-entry into the community and therefore what was a benign regulation of the cap that helped them while they were in is a barrier to leaving. It can also in some cases be an incentive to an institution of placement as opposed to remaining in the community.

Someone has \$250 of income a month, \$300 a month, they need a good deal of support in the community. They can't afford to pay for it. They're not eligible for medical assistance. That American might move into a long-term care facility because of the unintentional institutional bias of the eligibility process. There are a number of current initiatives, some of which address the above barriers of money and eligibility.

At the Federal level we have the Waxman-Pepper Bill, the Medicaid Community Care Act of 1979, I believe is the title. This Act essentially involves an assessment process of every individual who may require long-term care to see what their needs are and what their abilities are on the level of function and then it provides for an increase in Federal financial participation to

states of up to 75 percent. New Jersey is now 50/50. Under Waxman-Pepper we go to 75/25 for home-health based services.

When it was demonstrated that the home-health service was, in fact, the cost effective alternative to institutionalization, this bill would allow us to provide those services and it would solve the problem, largely solve the problem of the institutional path. It is a very good bill. It has very strong support from most of the states in the country. The American Public Welfare Association has enforced the bill and is pushing it very strongly.

Second Federal initiative Senator Bradley spoke of this morning, Title XXI, sometimes called Packwood-Bradley, in New Jersey called Bradley-Packwood. This is a very, very innovative and exciting concept. I would have to frankly say that I have some problems with the bill, not in its intention, but I am a bit concerned about fragmentation of the institutional care system from the community system and at this point, more inclined toward an approach which further expands Title XIX to enable it to more effectively provide home-health services and rather than a whole new

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title that would then have three titles active in the field, XX, XIX, and XXI, although I have to admit that before a conference similar to this about a year-and-a-half ago, I, in fact, advocated a title XXI.

Perhaps it was at our 1923 Conference, I'm not sure. I've done some more thinking about it and do have some serious second thoughts about the concept of Title XXI, not its intention, but its management implications as it would interact with a reality of our current programs.

The third important Federal initiative, and this is a Federal-state initiative, involves something known as "channeling grants." The Congress provided \$20 million a year or so ago to the Department of Health and Human Services to conduct demonstration grants around the country. The idea was to test out the concept of putting the total array of services necessary for an individual available in a one-stop shop following a complete evaluation of that individual's needs and matching those two up.

All of you know the fragmentation of the present system and the mine field that one has to navigate forward to get services and the fact that

we may choose certain options because we're not really aware of the other options available. Channeling is a simple concept and it's almost self-evident in its implications.

New Jersey fortunately was one of the 12 states awarded channeling demonstration grants. The grant has two pieces. One, the local service delivery site demonstration which, in New Jersey, will either be Essex or Middlesex County. That process is now under way. The process of selection with Federal site visits have happened in the last two weeks or so.

The second aspect of it and a very much smaller aspect of it in terms of finance is that New Jersey has contracted to deliver to the Federal Government at the end of a one-year period a plan for long-term care. This plan for long-term care will be the combination of the process that Ron Muzyk described earlier of a number of beginning to come together and trying to pay attention, more careful attention to this issue. The difficulty we have is that all of us are responsible for variety of programs and can't put the kind of time and attention and effort into any one program that it warrants.

One of the benefits of the long-term care planning grant is that it has enabled us to recruit some staff people who will work under the direction of Mike Laracy from my staff, working with the health department, Department of Community Affairs, Public Advocate, and so forth, and a wide variety of people in advisory capacity which is the process now under way to assemble that, to develop a comprehensive chronic care plan for New Jersey.

I have with me a copy of the Department of Human Services' report which carries a pretty good article on the Channeling Grant and they're available in the back of the room as you break for lunch, and I won't go into the details of it at this point. The article does it well.

A second State level current initiative involves revisions of the home-health manual by the Division of Medical Assistance to cover personal care services. For a number of years we had heard mysteriously that New York State had a very extensive personal care program that went much farther than we did and that we really should investigate it. When we did that, we were advised by our regional friends in H.H.F. that we really should model our-

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selves on New York because they may have been doing some things that went somewhat "beyond the pale" and they might be in for a big audit exception. We were therefore cautious and did not plunge in.

As it turns out and it often does in the case of New York State, I think the moral there is to steal big and no one can do anything about it, Federal policy moderated in the direction of New York State rather than New York State moderating in Federal policy. Therefore, we revised our home-health manual to contemplate the use of personal care services as an added way of getting more services out there and also relieving Title XX because not only could we substitute Medicaid for the home-health aspects, the Title XX had been paying for, but we could pay for some of the personal services that Title XX had been paying for.

The problem is, it has a \$4 million annual price tag. It has surfaced at the most unpropitious moment for the Medical Assistance Program because we're struggling with a \$50 million deficit right now. So that has put the personal care revision on the back burner for a little while.

I'm optimistic that all that hard work was not done for nothing and, in fact, we will be moving to a personal care program in the New Jersey Medical Assistance Program. I can't say just when, but I'm confident that we'll continue that movement, and we'll get there.

Dr. Trager's point about not viewing home-health as an alternative but as part of a system is extremely important and brings me to the last major topic that I want to share with you. Dr. Cluff pointed out that people are living longer in the United States and that that trend is likely to continue with the over 75 population growing at a much faster rate than the merely over 65 population. Both of those populations together are going to grow by about 50 percent by the year 2000.

We as a society have a choice to make. We have to decide how we're going to respond to the phenomenon of more and more aging Americans and how we're going to respond to the phenomenon of the societal changes that have put children in California, in Florida, in Michigan, and grandmothers and grandfathers in New Jersey, and grandchildren in France. It's a whole different

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world. How are we going to respond to that?

I think that we're going to respond to it by meeting those needs. Even in an era when absolute dollars in health care, perhaps, are going to be less than the -- the growth is going to be less than it has been, but I think inevitably we're going to invest in that system. If we continue present policy and practices in the United States, we're going to spend a staggering amount of \$24.5 billion by the year 2000. Notice I said "point five." It always makes it sound expert. \$24.5 billion in capital outlays for long-term care construction. We're going to spend \$70 billion a year averaged out over the next 20 years in operating costs for those facilities, \$70 billion.

In New Jersey we're going to spend \$600 million in capital, and that's in 1980 prices. You compound that at 8 percent and it gets astronomical. We're going to spend a-billion-and-a-half dollars in operating costs over the next 20 years.

The discussion about cost and benefits of home-health care versus institutional care perhaps becomes a bit beside the point. One way or

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another we're going to spend an enormous amount of money over the next 20 years. That confronts us with a great opportunity.

We have options. We have choices. We can decide whether we're going to simply repeat the practice of the past ten years, past 20 years, or we're going to do things a little differently. We have great options and great choices before us. I think that we really get off on the wrong foot when we get on to the argument, is home-health less expensive than institutional care?

For some people it is. For some people it isn't. As a society, I don't know. What we have to have is a balanced, rational view of what our long-term care policy is going to result in. What kind of a system we want to have in 1990, 1995, and the year 2000. Do we want the same system we have today or do we want a better system? Money is not the object. We have the money. We're going to spend it one way or another.

So I'm going to suggest at least my view of how we should in broad terms plan to spend that money. I submit this view to you as preliminary thinking. I've been going to meetings for the past two or three years where everybody is agonizing

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over the problems of long-term care and what are we going to do. What are we going to do? We're at cross roads. It seems to me we're in more of a traffic jam than at cross roads. Nobody seems to say, "Here's what you're going to do."

Being a very humble character, I'm going to suggest what I think we ought to do. Some of this is eclectic. I've stolen this from many people. That's what eclectic means.

As I see the chronic care system, we have to develop in this State, it has four inter-related parts. Number 1, it has the nursing home. I'll say No. 4, it has the nursing home. Number 3, it has the community care system, both social and health, and that's an aspect of what we're talking about today. Number 2, it has congregate housing. And No. 1, it has the family support system policy.

First, with regard to nursing homes, I think it's terribly important that in our justifiable concern, we should develop an appropriate alternative to nursing homes and we should not make New Jersey a wall-to-wall nursing home. We should not lose sight of the fact that there is an absolute need for additional, and long-

term care facilities in this State. At the present time there are 3,000 people waiting for placement in New Jersey with help from the Medical Assistance Program. These are people for whom there isn't a lot of option.

We are providing many of these people with home-health services that we can and patching together what we can to keep them together in the community while they're there, but these people need the kind of care that can only be provided in a long-term care facility, and we don't have the facilities. We have 5,000 facilities in the pipeline, what we call "paper beds" in the State and so forth, but people don't sleep in paper beds and we're getting better and better at managing the planning system with the real requirements of people, but at the present time, there's a mismanagement.

We can't lose sight of the fact that we're going to need some additional beds and that by investing in those additional beds, we won't do that at the expense of developing appropriate complementary systems. I won't call them alternatives, I'll call them complementary systems.

Within nursing home and environments, I

think we have to pay a lot more attention to what we call in our Department "normalization policies." I think if people are going to have to be in the nursing home, I think there are lots of things we can do to make it as normal as possible. One Monday, for example, people shouldn't have to line up to come to meals. When it is time to come to meals, in a long-term care facility, people who can come to the dining room should be able to come to that dining room any time they like, within a half hour, 45 minutes before the meal, and sit down. If you've ever been in a nursing home where people line up to go to meals, it's a very bad situation as people jockey their chairs and rumble into the room with the time and get to the table and swipe the desserts and so forth. Just common sense says you don't do that. That's what normalization is about.

Try to make the facilities as home-like as one possibly can within the necessary constraints of an institutional environment. I think that we have to address the question of cost reduction in nursing homes through some assessment of the standards, both life safety standards and the operating standards. We've been described as a

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fire company society. That means that after the fire comes, the barn burns down, we respond. We send the fire trucks. Perhaps what was really called for was a bit of fire prevention in the barn, cleaning it out once in awhile, but that doesn't suffice.

We adopt a standard and build concrete barns from thence forward. I think that we have to rethink that way of responding in a situation. Resources are too scarce to do that. Also, I think that the nursing homes should begin to be thought of, perhaps, as not the isolated institutions apart from the community, but perhaps as a hub of a community care system working in strong alliance with the home care system and the other alternative systems.

We in our certificate of need requirements recently published by Commissioner Finley in the health department now require new applicants for certificates of need to demonstrate their role in helping to foster a coherent community system in order to qualify them for some preferential treatment in applying for certificates of need and I think that's a very important advance.

Now, I know that maybe some sensitivity

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among various groups is involved. Who has the lead role? Who has the secretary role and so forth. I think that we have to overcome all that just by dialoguing together and working together. I don't think we can look to hospitals to become that hub of the chronic care system because they're just not really basically very interested in this area.

I think there is some responsibility of working with nursing homes and the other parts of the system that they can play an important role. The community health and social services system obviously has to be developed and that's what we're talking about today. Community care is less expensive for some but not all. It depends on the level of functioning. Obviously a person who requires this kind of care has to have an assessment. I think the primary candidates for community care should be people who either require minimum care on a long term basis to keep them independent from free standing situations or dwelling units, or for whom a high level of care for a brief period of time will offer the likelihood of a return to cell functioning or minimum care status.

I think that if more is required, the

congregate housing option or the long term care facility should be considered. In looking at the community care system, we have to pay very careful attention to the personal needs of that system, the personal needs of that system. We're going to need a lot of people to do different kinds of things in the future and the time is now for our secondary educational system and our higher educational system to begin thinking about those needs in the next decade and begin developing people who will find rewarding and fulfilling careers in this area and it is going to be clearly a very, very large growth area in the service sector.

The third option I think we have to talk about is congregate housing, and Ron Muzyk talked about service programs. They're beginning in their department working with congregate housing sites. We have to think massively.

Bruce Vladick, who's with us today, in his recent book, *Unloving Care*, which is the definitive policy history of nursing homes in the United States, he calls for the construction of 200,000 units a year in congregate housing. A large section of those congregate housing units, a large portion

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of that can be seen as an alternative to the 700,000 or a million long-term care beds that we're going to have to build in the next ten or 15 years, assuming present patterns continue.

Some of that congregate housing can be the alternative for those beds. We can build one and not the other. That doesn't say we don't build any long-term care facilities, but we can build some fewer number as a consequence of congregate housing.

I define congregate housing in this environment as something that provides specially enriched housing for the elderly and disabled. It involves help with meals, chores, shopping, visiting, and health services. It is particularly well suited and in my view for people who need moderate to high levels of community care, that they can be sustained in a least restrictive environment that is appropriate to their needs at less cost than in a health care facility.

I think an important philosophy underlying the nursing of congregate care is a philosophy of self-help. A lot of elderly people and disabled people can give strength and help to one another, and the opportunities of community

living makes that more likely to happen. In addition, obviously, if community care is going to be provided, it can be provided much more efficiently if large numbers of people who require that care from time to time can be together in a fairly close proximity as opposed to the visiting homemaker having to move to two or three places or the nurse to five or six places in a day. These facilities when brought together in one place can provide a way to do that a lot less expensively and I think in a lifestyle that can be quite normal and certainly far preferable to lonely isolation or the extreme security and protection but may be sometimes excessive in a long-term care facility.

The fourth part of this long view policy is a policy of family support. One dilemma in improving chronic care systems is how to provide diminishing appropriate support for family and friends. We obviously need a process to evaluate the needs of people seeking services both to insure the people most in need get help first and that families can continue to provide reasonable support. We should not discriminate against the elderly who have to reside with their family.

For example, in New Jersey we have several benefits that you don't get if you live with your family. You don't get a property tax exemption. You don't get Lifeline. What we should do is make these benefits portable; that is, if my mother lives with me, my mother's property tax exemption should come with her. My mother's Lifeline credit should come with her, not whether it would be the difference if she lives with me or doesn't, but it would be one small way for public policy to assist families who do reside together with their elderly members. In addition to being a social statement, it will provide a little bit of economic help as well.

I think that that's something we should put on the agenda today in New Jersey. We also got included in the rewrite of the Lifeline Bill this year, but it didn't happen and we'll try again this year.

We also need to assist families in more developed programs of respiratory care, preferably the care should be in the home rather than in the institution where we can put people in the home to assist rather than take the person out to an unknown perhaps threatening other place.

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In conclusion as we look at the long term of home-health care and chronic care systems, I think that we can provide the elderly, physically, and mentally disabled people in the United States and in New Jersey a decent affordable place that is least restrictive to their independence and freedom. A system cannot consist of alternatives. A system needs to consist of parts that work together in concert.

We need facilities. We need services. We need an ideology.

The chronic care system that I have outlined may or may not be less expensive than our current approach, but I think it will certainly be better. After all, getting more value out of dollars spent is an important aspect of the strategy of cost containment because the growing number of political influence and power of the elderly will bring strong pressures to build and to spend more in whatever system we fashion, and I think by building a long-term care system that works we will spend less than we otherwise were trying to satisfy the unmet medical needs that will inevitably flow from the continuation of our current, largely institutionally based approach.

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Thank you.

MR. SPECTOR: I will now ask Martha Darling to speak.

MS. DARLING: It always is left to the people from Washington to come and tell you the bad news. There was a statement that money may not be the object but it certainly is a constraint. Let me just try to fill in for you a couple of points that I might make as one who sits in Washington, D.C., and is aware of some of the trends that are of note in that town and the kinds of messages from out in the countryside that members of the Congress receive, or at least think they receive, from the mixed messages that come through votes and through various lobbying efforts by all manner of groups.

The first thing I would note is a growing awareness in Congress about the change in demographics of this country, the larger and larger percentages of the population that are going to be older. That awareness has not fully extended to the health care system, but it is going to hit them all in the face next year with the need yet again to consider how we're going to

finance the Social Security system.

Fundamental demographic changes mean there are going to be more and more retired people who are going to be receiving benefits as contrasted with those who are working and therefore paying into the system. Quite apart from the notion that Social Security is an insurance system, we now take the money in and we immediately pay it out. There is no insurance pool and therefore the growing cash flow problem is one of considerable seriousness. I think you're going to find in your members of Congress that they are very aware when you start talking to them about the changing demographics.

In some respects, we are preparing a way for you to go to talk to them about the needs of home-health care and related services as well. I think members of Congress are becoming more and more conscious of some of the numbers that have been talked about today.

Another trend of which everyone in Congress is aware -- it's been alluded to this morning on a couple of occasions -- is increasing health care costs. Some would say

rampant inflation in the health care sector. There are many contributory causes. One of them is the reimbursement system that's built into Medicaid and Medicare, fee for services.

There is high concern and I think this concern is something that will not change with the new administration. The growth in our health care costs is going to kill any administration unless changes are made in some way, shape, or form.

Now, a consequence of health cost inflation which is very important for the whole home-health area is that there is a considerable reluctance to put Federal dollars into programs of unknown shape and size. Everybody, even those members of Congress who were not there at the time, will tell you about the terrible learnings that came from Medicaid and Medicare. Many of them who were there will tell that they were, in effect, snookered into voting for these programs with claims that wouldn't cost very much and it would bring very needed services to the elderly, the poor, whomever the beneficiary group the arguer wanted to cite.

The fact is that there was not accurate

judgment, there probably couldn't be accurate judgment about what the demand, what the need for those services was going to be; nor, indeed, what the costs of those services was likely to develop into; nor the fragmentation of the kinds of services that could be offered; nor the wonderful, exciting technological break-throughs in the whole health sector and what you could do with machines to help disease prevention as well as disease treatment, nor their considerable cost. But nonetheless, all of these learnings work against any new program, even our Title XXI.

This is why we've designed it with a five-year demonstration segment in it, so we can find out what's going to go on.

We heard yesterday from speakers, and I think most people here would agree, that there is a lot of need, a lot of demonstrated need that you know is out there. If Federal dollars start coming much more on line, we're going to start bringing some of those people into the partially publicly funded system, which is good and proper. I don't think anyone disagrees with that agenda or disagrees with the statements about developing more comprehensive approaches. But there

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are a lot of folks down in Washington, let me tell you, who are very anxious about how much that's going to cost and where they're going to get the money from because one of the other messages they hear from the countryside is to get government off our backs. Don't tax us any more.

We have a new administration coming in which has promised the reverse, large tax cuts, which leads me to the question of how Federal budgeting gets done. All Federal budgeting is really done at the margin. We have in place large chunks of the budget -- Medicaid, Medicare, welfare programs, defense spending -- about 75 percent of the budget which is untouchable, unless we decide to reduce Social Security benefits. You can imagine how popular that is as a way to save money in Washington, D.C. So you have a large chunk of the budget that's untouchable, large chunks in addition which are held tightly by some very important programs and groups which come under the control of Senator Williams' committee, the Labor and Human Resources Committee.

I don't think you would find very much there that you would choose to cut in order to

fund your program. Most of those are discretionary programs. The National Institutes of Health which fund a great amount of the basic research which, with any luck, will continue to contribute to the prevention of some of the disabling conditions that people experience throughout their lives. Job training. Which one of you is going to get up and tell me which things we're supposed to cut in order to increase the funding in these other areas. I mean, I'm hard pressed.

Everyone has an individual list of suggestions, but if you can all get together and put together a list, I would be very surprised. This is something we've asked the governors, in fact, to come up with. What would they be willing to trade off for string-free Federal money? This is an issue which will come up in the Senate tomorrow, and we have to see about getting it passed because, believe it or not, that's very important to funding many of the health functions that you're concerned about as well.

They cannot come up with a list, and it's unreasonable of us to expect them all to agree. Similarly, it's somewhat unreasonable of us to expect the Congress of the United States to come up with a similar list.

Many of them would like to fund these services, would like to give a lot more money to them. The budget -- and Title XXI -- is going to be a question of negotiating, of looking at what our resources are, of pruning some of our social programs, because as I say, the demographics are becoming more well known to the Congress.

Let me also say a word about the savings from preventive services. There is no doubt that savings come with early intervention as opposed to late intervention, less intensive care as opposed to more intensive care. There's just no doubt. It's hard to prove to members of Congress, though.

One can talk about increasing services on home-health as a cost effective alternative, but that's an almost impossible thing to prove to the satisfaction of people who feel that they're going to have to unbalance the budget by another dollar because of additional expenditures. I'm telling you that because it is part of the Washington scene.

It's very difficult to argue for prevention because Congress and senators don't have a

very long time frame for their budget decisions. They're budgeting one year at a time. We need to look at the next decade, the next two decades, the next three decades. It doesn't happen very frequently in the Congress.

Congressmen are up for election every two years. It's hard for many of them to look beyond the polls or the next November, and for very reasonable considerations in their own minds. So theories about prevention being less expensive are sometimes hard to focus on.

Let me mention one last thing, the study that Dr. Cluff mentioned. This was a very controversial study. It has been challenged already by witnesses and testimony before various committees of the Congress. I don't think it has really locked itself on the consciousness of most Congressmen. We do need more extensive studies. Two years to look at some long term cost considerations is a little thin, even our five-year proposal in our Packwood-Bradley bill is not going to tell us a whole lot about what the cost is

going to be in the long term. So continued experimentation will be required.

I wouldn't worry about that study poisoning the waters yet. I think the budgetary considerations and the short term perspectives of a lot of members of Congress are more important. You've got a big education job to do. You've heard, those of you who were around yesterday, from Senator Williams and also Senator Bradley, both yesterday and today. Those are two Senators who are aware of this issue.

They are not followed by legions of their colleagues in that awareness as yet. I think it would be appropriate for you to go see members of the House from New Jersey. Where you've got organizations in other states, you've got an education job to do with their members of Congress. I think with education we've got some prospects for being more comprehensive in the way we're thinking about these problems at the Federal level. Most especially, the kinds of projects that you by your entrepreneurial ability and good will have managed to fashion at your

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local level are essential to moving these ideas.

When we hear about the visiting nurse service in Elizabeth, when we hear about demonstrations in other states, like Triage in Connecticut, the Wisconsin projects, those are the things that, as they knit together, as that information becomes more well known across the land, are going to make it possible to get more movement in the Congress. We envision our Title XXI as a start on that. It's not nearly as comprehensive as many people would like, but then again, we've got some real concerns about making sure that it's as reasonable as possible in order to be passed in the next Congress.

So if we are a little defeatist in Washington, understand where we are; and forge ahead because it's what you folks are doing that is going to allow the people in Washington to start moving with much greater resources and in the directions that are needed.

Thank you very much.

MR. SPECTOR: We just have a very little

bit of time before the captain signals me from the door. I would like to thank the speakers very much for sharing their time and talents with us. The Governor has left for me to give to you as a small token of his appreciation for that very sharing, and I'll do that now. They're all the same.

If there is some response from one panel member to another or to the group, I'll entertain that briefly now.

MR. REILLY: Just a point about that we can't be unmindful of the cost. I absolutely agree with that. We can't be unmindful of the cost. Sometimes I wonder if we're caught in an empirical trap where consensus really hasn't built broadly enough for to decide if we're going to do something, therefore we study it, we study it, we study it and they'll be enough studies that will prove different things on all sides of the issues, but it will at least throw enough dust in the air that we decide not to move.

The point I'm trying to make is that if we do nothing, we will move. We'll move our predictable current pathways. We will have those enormous expenditures. And we'll have a system

just like we have now that we don't like so that we have to begin thinking not so much in terms of cost benefit of home-health, because I don't think -- I frankly think home-health is more expensive than institutional care, but it is better in certain situations.

It is consistent with what I think we owe as a decent people to our elderly citizens and we should be spending a little more on the side for home-health care from time to time for a more congregate setting, but it's going to be far better for people, but I think if we don't move to change that simple cost benefit analysis, we will not move at all and be awake. You will in 1990 have 1.4 percent on home-health care and 95 percent on institutional care.

That's really my point. Don't look at the money as a constraint. It's a constraint, but it's also a resource. We're going to spend it one way or another.

MS. TRAGER: I'm glad to hear you say that the Weisser Report has not really captured the total brains of our Congress because as a consultant to those projects, and when the report came out, of course, everybody started, my phone

was ringing off the wall. "Aren't you going to do something?" and I kept saying, "Nobody's going to take it that seriously."

As it turns, out, it has been rather widely distributed but there are some term flaws in it, not just the fact that it's a two-year study, but actually the intrinsic projects themselves had problems.

In the next issue of the Home Health Services Quarterly because everybody was upset, we had gone to press already but we opened it up, There will be a supplement in that issue and many of the participants in the projects as well as the other people who critiqued it will appear, will discuss it in a little more detail and then in the spring issue, I'm going to talk a little bit about my experience as a consultant and what some of those problems were.

It's not a terribly accurate report. That's no reflection on Bill Weisser. It's just simply what he was given and what he had to use is not something that we need to take all that seriously because it really would be tragic if we did.

MR. SPECTOR: Anyone else at this point?
Questions, comments?

DR. CLUFF: Could I just make one comment?

In response to Gerry, I agree with everything Gerry said but I do happen to believe that now and increasingly in the future, in order to justify the expenditure of public funds for any program, one may not necessarily have to prove cost effectiveness, and I'm not even sure as I pointed out with that health care system, but I think one's going to have to be certain that one knows that the services provided are different effectively and efficiently at a reasonable cost and that the services' providers can, indeed, be readily shown and proven to have an influence upon the lives of the people served, and I don't think that's going to require just anecdotal stories. I think it's going to require more than just "I knew Mother Jones out there and I have no question in my mind but that she got better."

I think it's going to require some reasonably good analytical work to try to demonstrate that the services provided are delivered effectively, efficiently, and at a reasonable cost and that the people who are being served are actually improved and can be shown to have done so.

MR. SPECTOR: Any more comments? Okay.

Enjoy your lunch and be back here at 1:30, please.

(There is a luncheon recess.)

STATE OF NEW JERSEY
DEPARTMENT OF COMMUNITY AFFAIRS
DIVISION OF AGING

1980 CONFERENCE, : TRANSCRIPT
: OF
HOME-HEALTH CARE : PROCEEDINGS
:
IN NEW JERSEY : VOLUME II
- - - - - X

Educational Testing Service,
Henry Chauncey Center
Carter Road
Rosedale, New Jersey
Monday, November 24, 1980
9:00 a.m. - 4:00 p.m.

S P E A K E R S:

NATHAN J. STARK, Undersecretary U.S. Department of
Health & Human Services

DR. JOANNE E. FINLEY, Commissioner of Health

P A N E L I S T S:

JOSEPH LE FANTE, Commissioner of Community Affairs

T. EDWARD HOLLANDER, Chancellor of Higher Education

DR. STANLEY BERGEN, President, College of Medicine &
Dentistry of N.J.

ANN KLEIN, Commissioner of Human Services

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WINIFRED LIVENGOOD, Home-Health Agency,
Assembly of N.J., Inc.

JUDY LYNN FLOWER, C.S.R.

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A F T E R N O O N S E S S I O N

MS. LIVENGOOD: The meeting is going to be called to order.

I'd like to introduce myself. I'm Winifred Livengood and I'm the executive director of the Home-Health Agency Assembly in New Jersey that represents all the agencies that Rita described to you this morning. I guess this conference means as much to us as it does to anybody in the room, and I want to express for the Assembly again our thanks to the Governor and to senators and particularly to the Governor's Cabinet, many members of whom are here today, for giving their time and expertise to this problem which we're glad to know is now beginning to be more universally recognized as a problem.

Jed and I have shared the day, and so for this afternoon I will be moderating the events of the afternoon. My first very happy task is to introduce our luncheon speaker. I'm very honored and privileged to have Nathan Stark with us today. As you all know, he is undersecretary of H.H.S. and has made the trip up from Washington today and we're very grateful for your coming.

Those of you who may not know all the

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details of his background in the professional field, first of all, he's a lawyer, so we have a sharp mind on some of our problems today, and he has been president of the health center at the University of Pittsburgh. He has also been chancellor for health services at the University of Pittsburgh and prior to that, he was in Kansas City and was chairman of the Board and president of the Crown Center Redevelopment Corp. He was a very busy man in his spare time as senior vice-president of Hallmark Cards, Incorporated. He established medical schools and coordinated hospitals and served for fifteen years as chairman of the planning in Kansas City, so we are very honored to have a man of such distinction in the health field for so many years, both as professional and as volunteer.

Mr. Stark, welcome.

MR. STARK: Thank you. I must disabuse the audience of one thing. I didn't get fired. I left all of those jobs voluntarily. From Hallmark I can bring you greetings.

A funny thing happened on November 4. It is called a Presidential election, and although it has been more than two weeks now since the voters

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made their choice, we are still assessing the consequences.

Of course I accept the verdict rendered by the American people, but I would be less than candid if I did not say I wish it had been otherwise.

Someone once said that the difference between winning and losing an election is the difference between beating a train to the crossing and almost doing so. Earlier this month the Carter Administration did not make it through that crossing, and as a result there will be many changes in Washington--policy changes in the foreign and domestic arena--but the business of Government will go on no matter who holds the reigns of power.

I will not be in a position in the next four years to help direct the Department of Health and Human Services, but I have some feeling for the problems the new team will encounter. Elections may change the personnel, and even the policies, but they do not erase the issues, and the issues before us today are among the most important we will face in the new decade.

That is why I am pleased to join this impressive group as you discuss the policy issues related to home-health care. I hope I can

contribute to your debate by offering some observations on the somewhat broader issue of long-term care of which home care is such an important part.

The large number of you participating in this meeting attests to the growing recognition that long-term care is among the most critical social welfare concerns facing us as we move into the 1980's. Indeed, long term care may well be the issue of the decade, for as our population grows and ages, the problems of the functionally impaired will be a challenge to all levels of Government and to every part of the private sector as well. Every one of us knows the home-health industry will face its share of those challenges.

The sheer breadth of the issue has been brought home to me time and time again over the past year while I chaired the Department's long-term care task force, and I would like to begin my remarks this afternoon by telling you a little bit about the work of that group.

Composed of top-level officials from every component of the Department, the task force was charged by Secretary Harris with a straight-forward assignment: to recommend policy directions

that would move the Department forward in establishing a comprehensive, cost-effective and compassionate system of long-term care.

We began our work by conducting an inventory of all activities in the Department related to long-term care and then assigned eleven staff work groups to research, analyze, and report on the policy, programmatic, and fiscal implications of these activities.

I also recall a figure which was amazing to me of the number of programs throughout Government that was relayed to our aging population. There's someone 134.

Second, recognizing that all expertise and wisdom does not reside in Government, we requested and received briefings from representatives of approximately thirty organizations concerned with long-term care, in order to determine what they regard as the most critical issues facing us all in the 1980's.

In long, and often heated, meetings throughout the summer and fall, the task force members digested the vast array of data and recommendations that each of the work groups had produced. In the end, we hammered out some basic

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agreements on the direction the Department should take.

The long-range thinking initiated by the task force, within Government and without, will continue well into the decade, for issues as complex as long-term care are not resolved in one year or even four years. What is most important, I think, about the work of the task force is that we have begun to understand the full extent of the problem and we have generated some consensus about how to approach it.

We recognize that six million Americans are chronically ill and functionally disabled and that they require some kind of assistance with household or community activities or personal care. Two million individuals reside permanently in institutions and up to 500,000 more in need of long-term care services may be uncounted and largely uncared for in boarding homes or literally "on the street."

I believe there is agreement on the major objections of a long-term care system to meet the needs of these people:

It should promote maximum feasible independence for individuals in making decisions

and in performing everyday activities.

It should provide services in the least restrictive environment, preferably at home or in local communities.

It should assure appropriate, cost-effective, accessible, and humane care to everyone who needs it.

And finally, it should encourage and support the care provided by family and friends.

The Congress, Government officials at all levels, consumers, and providers generally agree that the present long-term care system often fails to meet these objectives. The problems are numerous.

The "system" is fragmented and confusing. There are serious service gaps. Too many people can't get appropriate community services, even when they are available.

Public policy has favored nursing homes at the expense of alternatives. Many states spend over 50 percent of their annual Medicaid budgets on nursing-home reimbursements, while only 1 to 2 percent of the total program resources for Medicare and Medicaid are expended on home-health services. Some people receive intensive services in institutions well beyond what they actually need,

because there is no place else for them to go.

Most long-term care services are provided by families and friends, but current Federal policies do not explicitly acknowledge their contribution and often work against it. Despite some progress, quality assurance remains a serious problem.

Current medical education, training, and practice too often emphasize that which is inappropriate for the complex problems of the aged and the functionally impaired. Too little attention is given to the comprehensive needs of the clients, to the possibility of prevention, and to the non-medical aspects of the problem.

Costs are rapidly increasing. Recently, nursing homes have shown the highest cost increase rates of all health providers. As prices rise, people on fixed incomes exhaust their life savings quickly, spend-down personal resources, and become dependent on public assistance.

We know there are no simple solutions to these problems. Impediments to the development of more effective policies and programs are deeply embedded in present financing and delivery systems. These can be removed gradually, but only through

the concerted efforts and cooperation of the Federal departments and the Congress, State and local governments, and the private sector.

Those concerned with long-term care agree that the situation and the system must be improved even if they do not yet agree on how to do it.

Movement toward a set of solutions will probably be guided by several generally accepted premises:

First, long-term care service delivery must be extremely flexible in order to respond to the wide-ranging variations in people's situations and the changing nature of their needs over time.

Second, an adequate long-term care system should focus on individual needs and consider housing, income, and social and health services. Similarly, all potential resources, including informal supports, should be considered.

Third, settings other than nursing homes-- private homes, small group homes, day hospitals, congregate housing, and day-time care--must be recognized as desirable from both a cost and quality standpoint for some people.

Fourth, we live in an era of scarce resources. Therefore, reallocation of resources already being spent is critical and we need more

effective public-private partnerships and a new system of incentives.

Fifth, the family is and will remain an essential provider of long-term care services. Public policy should explicitly recognize this role now and in the future.

Sixth, health care is costly, and long-term care services should be provided by the traditional health system only when necessary. In the long run, the establishment of a sound long-term policy may require a sharp break with current programs, although a Federal-State partnership will remain critical to the successful implementation of a long-term care service delivery strategy.

These principles will guide the further development of a Federal strategy to improve long-term care in America. You have, perhaps, noticed our emphasis on non-institutional alternatives. Currently, we are designing or have in place several demonstrations across the country designed to stimulate alternatives and assess their cost-effectiveness.

Since 1978, we have collaborated with the Department of Housing and Urban Development on a joint demonstration program to address the special

housing and community support service needs of the chronically, mentally ill. Under the demonstration, a combination of small group homes and clusters of apartment units will be constructed or rehabilitated.

Recently, a number of community-based independent-living projects, supported by departmental grants, have been initiated around the country. They will provide and coordinate services to assist handicapped people in minimizing their dependence on others.

The Farmers Home Administration, in cooperation with the Administration on Aging, is supporting congregate housing demonstrations at ten sites. Projects will open for occupancy soon and will provide full or partial meal service, house-keeping and personal care services, transportation, and social and recreational activities as well.

Finally, the national long-term care demonstration will help to develop the capacity of states and local communities to manage and coordinate efficient and effective delivery of long-term care services. The program will allow the Department to evaluate innovative approaches to planning, organizing, and financing long-term care at the State and community levels to see if these approaches

should be incorporated into new legislation and policies.

The long-term care demonstration program is a particularly significant component of the emerging national strategy. Our Department's recent awards to twenty-seven states--almost \$1 million in grants here in New Jersey--represent a major effort to pave the way for an improved partnership with states and local communities as we build a new system.

In the coming years, however, perhaps the greatest challenge facing us is the development of a consensus about the appropriate roles for the public sector and the private sector in caring for those who are frail and dependent.

The private sector is already heavily involved, of course, private nursing homes have and continue to dominate that industry. In the areas of home-health and homemaker services, we see the private sector involvement growing. And finally, we cannot overlook the role private industry plays in providing public housing to our long-term care population.

Let me stop at this point to focus my remarks to a greater extent on the question of

in-home care.

From my perspective there are three fundamental problems which must be solved before we can make long-overdue progress in this area.

The first problem seems elementary: We need some commonly agreed upon definitions of what it is we are talking about. At this point, when we say "home health," we can be referring to homemaker services or any combination of them.

Under the four Health & Human Service programs, Titles XVIII, XIX, and XX of the Social Security Act and Older Americans Act, that impact on home-health care, different regulations and definitions of services create problems of coordination.

An example of this problem can be seen in the following: Medicare, Title XVII, permits home-health aides to perform certain household chore services to prevent otherwise unnecessary institutionalization if it does not substantially increase the time that the aide is in the home. Title XX covers home-health services so long as they are integral but subordinate to other social service needs. Clearly, we must move towards common definitions if we are to coordinate and monitor

home-health services.

Second, we need to tackle the many issues which revolve around the quality of care. Here I would draw a distinction between standards and requirements and say that my preference would be that we concentrate on the former. Standards focus attention on what we must do to offer quality care to people, rather than on what must be done to keep programs in line. Standards offer us goals to achieve, rather than rules to obey.

Standards can be implemented in two ways: by working with policy makers, such as you, and providers to develop acceptable standards which providers will want to implement, or encouraging the implementation of standards with positive incentives such as favorable reimbursement. I should say that Federal incentive reimbursement would require legislative changes since most programs are based on State population and income levels.

Third, we must come to grips with the problem of conflicting eligibility. Just as the lack of precise definitions and standards can hamper the home-health trend, the absence of clear eligibility requirements can cause problems. An aged, poor individual, for example, can be entitled

to services under Medicare, Medicaid, Title XX, and the Older Americans Act.

Data is not available to indicate whether this overlap actually results in the duplication of services to the client. And a much greater cause for concern than potential duplication is poor coordination of services for clients who might be served by more than one program.

The questions about differences in eligibility pertain more to the income eligible population than to those who are categorically eligible, i.e., over the age of sixty-five. People become eligible for services under different programs at varying income levels. For instance, in one state, Medicaid will provide services to a family of four whose monthly income does not exceed \$233, while Title XX can provide in-home services to the same-sized family with a monthly income of up to \$795.

Federal, State, and local policy makers must continue to work together to resolve the issues of services definition, standards, and eligibility, but, perhaps, the most critical issue facing us is that of financial support for home-health and other non-institutional long-term care services. This

problem will require creative thinking by all of us, in and out of Government.

I think that the private insurance sector has only just begun to glimpse the ramifications of long-term care needs among our increasingly elderly population. Home-health coverage in particular is not widely available. Part of our job, clearly, is to encourage private insurers to explore options for accommodating the shifting trends in health-care delivery.

I would like to conclude my remarks this afternoon by suggesting some other areas that would benefit from your creative support, for concerned people like you can play an enormous role in helping to develop a national long-term care policy.

Initially, I think it is safe for us to assume that State and local Government officials will have increased flexibility in making decisions about the kinds of health and social services to provide to their citizens. We need to have more sessions like this, so representatives of the Federal, State, and local Governments can compare notes, exchange ideas, and plan coordinated strategy in the years ahead. It may sound trite to say we need a partnership in this area, but it is true

nonetheless. In a period of scarce resources, we must make every dollar count, and that will only happen if we work together.

Second, the movement towards non-institutional service settings will clearly generate a whole new set of in-home and community-based services. Some will prove to be viable; others will not. We will need to explore various ways Government at all levels can promote the strongest and most promising of these innovations. That will require both creativity and flexibility on the part of all of us who care about this issue.

The initiation of new services will bring with it new problems of quality assurance and this is another area that I would recommend for your investigation, debate, and leadership.

If we are to have a unified national thrust in the area of long-term care policy, we need to bend over backwards to ensure that careful, painstaking coordination occurs every step of the way. We need the help of policy makers such as you if we are to keep track of what is happening throughout the country, thereby allowing Federal, State, and local Governments and the private sector to learn from each other.

I am confident that if we all work in partnership, we will have a system of long-term care services that is comprehensive, cost-effective, and compassionate.

I am confident we will work together-- Republicans and Democrats, foundation directors, corporate executive and bureaucrats--in service to those vulnerable Americans who need, and deserve, our help.

I read a quote just the other day that I thought was very appropriate to this and any other meetings like it. It goes like this: "It is not enough for a great nation merely to have added new years to life. Our objective must also be to add new life to those years." John F. Kennedy. Thank you.

MS. LIVENGOOD: Thank you. That was definitive and challenging and something that makes us feel we might get somewhere. That's from a man who's been on the volunteer and public sector, and I really think what you say means a lot. I'm sure you all join me in thanking you.

As you all know, yesterday afternoon prior to the conference starting there was a hearing over at the Center for Health Affairs that was chaired by

Senator Williams and Senator Bradley. This hearing was on long-term care, home care, Title XXI legislation. Providers and Government people had a chance to discuss with the two Senators pending legislation and the kinds of things that we hope could be done. I think it was an excellent hearing and as Senator Williams chaired that, the questions he and Senator Bradley asked of the panelists were certainly penetrating and brought forth even more, I think, constructive, at the same time controversial, issues which will enable them to probe even deeper into the problems as they develop this legislation, which they do term as "developing."

The Senator was called back today because his transportation legislation is hot issue and there were some problems, and he sent his regrets that he would not be able to join us for this part of the conference. Three members of his staff and committee staff are here today, and I'd like to introduce them, because they're going to play part of a role here this afternoon when the panelists come. I'll just introduce them now:

Letitia Chambers who is going to do a wrap-up for us at the end for the Senators; and Tom Lindsey, who has been so helpful in all the

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details of this conference; and Kathy Degnan, who's an old friend of ours in home health in New Jersey who is from the Committee on Aging and is here to help moderate the afternoon. Senator Williams did make his regrets, but he has not been ignoring the problem at all and taking very strong leadership.

It is my great pleasure, now, to introduce Dr. Joanne E. Finley, Commissioner of Health, State of New Jersey, an old friend to home health and public health in particular, and we look forward to her major address to us on the topics of long-term care, home care, all that we've been hearing about. I know she needs no introduction.

DR. FINLEY: My job is going to be to bring everything you've been hearing actually for the last couple of days down to home base, and that's New Jersey, and tell you how I think that, first of all, I hope, Nathan, that our train does cross the crossing a year from now, because all of the things that are going on in New Jersey are worth carrying on, and it's going to be, I'm sure, important that we do so.

Now, I'd like first of all to start this particular conference on a much more personal note

than I usually do, but it will help you understand where in the field of long-term care and home-health care, particularly, it will help you understand where I'm coming from and why I feel so strongly about it.

A conference like this is good for me, and I think it's good for all of us because it brings back not only why I believe in what this conference is for, but also it makes me realize how much I've had to learn, even though I'm a professional and I'm supposed to be in the know. So I'm going to recite some personal experiences and needs, and I'm going to ask everybody in this room to think about their own personal experiences and the personal needs that they have been through, because I have a feeling that there is hardly a person in the room who has not been touched by the need for HELP, H-E-L-P, and has found that presently in our fragmented system it is not there.

Now, when I first served as a health commissioner of a big city in the Middle West, it was before Medicare and Medicaid. Then and there it was just absolutely categorical and expected that the public-health nurses who were the backbone of the whole health department were doing home-health care. For example, in a not terribly funded, even

at that time, Middle Western city it was mandatory that all premature babies' births be reported to us and it was automatic, regardless of race, creed, color, or income, that public health gave follow-up care, education to the family, and went as long as was necessary to make sure that those premature babies would grow up to be able to be healthy and productive.

Everybody who has been talking about home-health care is new, but to me it's not new at all. We're just rediscovering it. That was my first experience, administering a department like that. Then I moved, about the time that Medicare and Medicaid were passed as national law and were being implemented, I moved to the City of Philadelphia and worked in public health there and this city, of course, had long since been through its famous study and work in integrating the visiting nurse and public health nurses and homemakers, I might add, into the community nursing service, and, as a matter of fact, that had been a subject of a very interesting book, so, again, I came simply assuming that all of this was a public health role.

And then I had occasion to educate the medical profession when our eleven-year-old, now

nineteen, was hit on his bicycle coming home from school and ended up at Children's Hospital in a body cast from here to there, and when I had to tell the famous orthopedist who, as a matter of fact, became quite famous when he helped separate the Siamese twins later, that after a necessary period of hospitalization, I was going to bring this boy home because I knew that I had the Community Nursing Services and he had to say, "What's that?" So I participated in my own learning process.

I'm a physician. I'm a pediatrician by clinical training, but there I was a mother and also a pediatrician, and darn it, I knew that was better medical care to have my boy at home. But at the same time in listening today and preparing for this meeting, I really didn't, being that personally involved and insisting we were going to have home care and getting very good home care and having, of course, the affluence to have a housekeeper, who, along with working mother, could be trained to do the physical therapy so that when the cast came off, he would begin to be able to learn to walk again.

But I didn't really realize, I didn't think about it, that A, it was connected to an acute hospitalization, and B, as I say, there were people

there. I didn't really translate my own son into the kinds of needs that you have been properly discussing, and for that selfishness, I apologize, but again, I always just expected that long-term and hospital care would be there.

Now, recently I have had a much more--much less productive experience and this, I think, will really illustrate where I am coming from and why I will be proud to tell you what we are doing in New Jersey. Although I'm the health commissioner, and this is supposedly a very exalted perch, I have experienced an eye-opening awareness of what is involved when you struggle virtually alone and even though knowledgeable to arrange the necessary aspects of care for a disabled family member. This, again, is where I say I think practically, if you will think about it, every one of you in the room has been touched by something like this.

This has been and continues to be an excruciating experience, and Miss Trager, when you said that this morning about family members somehow keeping their chins up but ^{are} getting tired, I can empathise. If anything has restored my sense of crusade as to the need to redefine, rediscover, and then go into the kind of future that Nathan Stark

talked about with continuous support services for disabled individuals and their families, our own experience has done so. And previous speakers have really said it very well, but I want to bring it home. We have a very minimally brain-injured son from a very unnecessary obstetrical accident. Productive, working, doing fine, therefore some private health insurance, but not quite a year ago he was mugged in Newark on his way home from work.

Now, there is something called the "catastrophic reaction" of the neurologically impaired or the brain-injured and this, indeed, happens. People who are coping but are chronically disabled when subjected to that kind of stress are almost just bound to go down the drain.

This young man was living in his own apartment, but alone. Support services were minimal. Family was nearby. And he was and is enrolled at a very productive rehabilitation program at the Institute for Rehabilitation Medicine in New York. New Jersey will have a similar program shortly so that I don't seem to be unchauvinistic about my own State. We are hoping to help get it started in our Department. But at any rate, you can imagine that A, having to close his apartment, B,

bring him back to live with us, C, trying to work with a traveling husband, D, trying to find just one little need, somebody to continue to take him to New York twice a week, because he wound up at his appointments in the dark and he was afraid that he would be bopped over the head and have his medicine and his glasses stolen and his clothes torn again.

Then I learned full-force that--oh, E, that his Major Medical would run out, which it has. I think here, knowledge made it possible to become the group we are together of all of this, but really what do people do who do not have the one agency to turn to who can glue all this together for them? Further, something as simple as I say just an aide to take him to New York, how tragic that here our home-health aide services are so divided, and I guess I can say that because everybody in New Jersey knows that I have always felt that way. After all, in Cleveland and Philadelphia, it wasn't like that.

Now, with that background, which, as I say, I really don't normally share, I don't even think my staff in the Home-Health Department knows about all my own experiences. I thought I would tell this audience because now you know I really understand and I really care.

As I say, it's kind of fun. I always enjoy discovering crusades or rediscovering crusades. I don't mind being called a "crusader," and now I have won all over again.

Now, my job, as I said, is to bring this whole meeting down to what is going on in New Jersey, and then you will hear from representatives from our Congressional Delegation and from our other State agencies who will react to what I've had to say.

I'm going to divide the topic into sort of three categories that one flows from the other very logically. The first is: What are the coordinated planning activities with other departments and with the private sector that have been going on?

Secondly, how does this lead or flow to dealing with reimbursement and payment mechanisms which I'm not going to have to belabor because you have heard a great deal, both in New Jersey and in the Nation, about what kind of flaw or fault, and when I talked about what we did in the Middle Western city before there was Medicare, please don't think I'm talking about going back from that, but it's funny how often financing mechanisms desert

participating programs that were there and properly running in the first place.

Anyhow, from there I will talk about some specific things that our Department has proudly been doing with minimal funds and a lot of good will between the Home-Health Assembly, for example, and our Department to help get home-health services ready for this future that we believe will come and ready in terms of sharpening up their management skills.

All right. First the planning process. Most of the people in the audience who are from New Jersey are aware that this State had the great, forward-looking, beat-the-Federal-Government-to-it, and we hope to keep on beating the Federal Government, but in 1971, a Health Facility Planning Act was passed in this State that is very much in its philosophy and thrust like the National Health Planning legislation of today. This placed the State health-planning responsibilities and other aspects of health system, health-delivery system reform in the hands of the State Health Department and created also, of course, what today we call the "State Health Coordinating Council" and the "H.S.A."

Now, therefore, we have had the good

fortune to have a process going on since 1971, and we were quite ready to meet the requirements that a state health plan be developed. One of the aspects is the long-term care limit and, as a matter of fact, much of its implementation happens to be a priority that this thirty-four person, state health-coordinating council, citizens from all over the State, have developed.

I will just read you certain things from the long-term care plan limit, and I hope that you will see how--of course, its rhetoric. It has to be translated into reality, but how forward-looking it is.

First of all, the lack of sufficient alternatives and settings to nursing homes is mentioned, often resulting in appropriate utilization of these facilities. A recent survey, a study completed in early 1978 for the New Jersey Medicaid program included that 35 percent of long-term patients currently institutionalized at just intermediate level in the State could be discharged, and then a recent survey from Detroit is also mentioned. This is in our own State plan. That cites 40 percent of unnecessary institutionalization.

The social trend towards institutionalization

has been exacerbated by existing funding patterns. You heard all about that this morning. We said it two years ago. Present medical reimbursement structures make funds readily available for institutional care, but not for in-home care, and this is being said again.

There are few established linkages from transfer from persons in hospitals from long-term care facilities to home-health cares, physicians traditional prefer in-care health programs. I think when you talk or have the Panel this afternoon, you will have both Dr. Bergen, the president of our College of Medicine and Dentistry of New Jersey, and you will also have the Chancellor of Higher Education, and certainly you will want to ask what is being done about the training of physicians and other health professionals in our State, not just for geriatric medicine, but for any community medicine as I would define it.

I happen to have had my public health training before I went to medical school. I did everything backwards, but I'm glad I did. I was an economist before that. Economist, public health, and medicine. It all fits together beautifully in this day and age.

I used to get called a "social worker" when I was a medical student, although I went to a school, Western Reserve that really was interested in teaching community-based medicine. I'm not sorry that I did, because it meant I was always thinking of other kinds of community services that we as medical students and physicians should be recommending.

On the other hand, I had the good fortune to go to Reserve under the Commonwealth Fund Grant which did have us practicing to be doctors in something called "Family Clinic" or "Group Clinic," and so on and so forth, and while I was the only one, only student who knew what the public health nurse was there for in our clinic, other doctors learn.

What you do in medical education is critical, and anything I read from our own State health plan about what's the matter or what doctors are used to doing or don't do right about all of these things, really has to be traced back to how they learn and hopefully how they learn in teams together with other kinds of health professionals.

Anyhow, we went on and on in the State health plan. I must say that the State Health

Coordinating Council has a good flavor of both mental-health people and of home-health people.

The current president of one of our H.S.A.'s is a home-health agency health nurse and is present in the room today, and I think it's good that our State Health Planning Council has that flavor, but it's there. It is not, indeed, just a long-term health-care plan for how do we decide how many beds we need, although that has to be considered, too.

So the goals established by the State Health Coordinating Council a couple of years ago to do something about these problems led a number of State officials to begin meeting informally. The group included the representatives of the Department of Health, the Department of Human Services, Community Affairs, insurance, and the public advocate, and their purpose was to continue to systematically address long-term care issues and the necessary policy initiatives to deal comprehensively and on a physically sound basis with the needs of both our elderly and our disabled.

Now, the group first concentrated on the preparation of the Channelling Grant demonstration application which I believe Gerry Reilly gave you a

good many details about, and I will simply recognize again that of the two sides proposed amongst which the Federal Government has to choose for being the demonstration site to implement this grant, one, the Middlesex County one does, indeed, propose a subcontract for a whole variety of services with home-health agencies.

Now, I'm not giving a plug for one or the other, but I was saying at lunch that since I feel, and you can understand why I feel this way, that the long-term care services, the home-health services must address the needs of the younger population, also, particularly, quite frankly, those with the potential to continue to be productive or be returned to productivity, and certainly with that--I hate the work "cost effectiveness--" but with that value for our society.

I really do feel that we should place our demonstration where we are dealing with a spectrum of age groups, although certainly I am very much in favor of all the necessary attention to our older population.

I bless Nathan Stark for speaking so strongly about housing needs and knitting other kinds of care together with those sorts of

demonstrations, because even in the case of my own boy, let alone other people we know who really cannot function all alone in their own apartment or own homes, but who desperately want to do as much as possible, are proud when they can, I think honestly housing comes first and then build an array of the necessary health services around it. Housing, good housing with good support is conducive to good health.

Now, you also recognize that one of the things that must be done, one of the State's responsibilities, having received one of the fourteen Channelling Grant programs, is the further development of a comprehensive State long-term care plan, and I can assure you what you all are discussing today will, indeed, be part of that plan and certainly part of our thinking and continue to be. And thus, this informal working group has turned into, in a sense, the steering committee that subsequently was provided for, the interagency task force, that was provided for in a bill passed by Senator Hagedorn, a member of our own State's institution's Health and Welfare committee in the Senate, the preamble of which says, "The effective, appropriate provision of home-health care and

homemaker services to persons in their homes can be an important step toward eliminating not only the nursing-home bed shortage which currently exists in this State, but also preventing the inappropriate placement of our citizens into other forms of institutional care."

Now, I know that the Home-Health Agency Assembly of New Jersey under Winifred Livengood's able guidance has expressed an interest from participating in working groups with the task force, and I do not see any way to accomplish the mission that is set forth in Senator Hagedorn's legislation without including you and yours, and I think you know we mean that. This task force will be obligated to develop the statewide long-term care plan by October, 1981, a month before the train must go across the track, the car must go across the track and the train stay down there in New Jersey, because we are devoted to carrying out what we set out to do. We have that work cut out for us.

I think I do not really need to say a whole lot more about payment and reimbursement mechanisms, because all of you, the private insurance companies and Medicaid, Medicare have been charged over and over again with the need for this sort of reform.

You have also heard a good bit from our very able Senators and their representatives about the intent of both the Packwood-Bradley-Williams Bill and the Waxman-Pepper Bill to deal with some of these issues. I'm sure yesterday in testimony everybody heard somebody's opinion about a few bugs in both these bills, but I think we would all agree that they are entirely on the right track, and incidently, as a physician, I have never been known to feel that the medical profession knows how to do it all, and many people in the room will probably laugh, because I'm always taking on the medical profession in behalf of nurse practitioners, in behalf of nurse midwives, and so on and so forth.

I do think that perhaps one of the bugs, one of the lessons that we should have learned from the past in terms of the roles of physicians in relation to nursing homes is not to go and repeat this sort of multiple role of administering, regulating, making medical management plans and so on and so forth for physicians who really haven't had the education to deal with the problems and to just go ho-hum and give part-time. I certainly think doctors are important but I think, again, a teamwork arrangement is preferable; however, in

terms of reform of payment mechanisms, I will mention a couple of things that the Channelling Grant proposes and that the task force--Senator Hagedorn set up the interagency task force--says must be done and must be in a plan by October, 1981.

The desirability of altering Medicaid eligibility standards to remove disincentives to in-home for community services. Two, the need to balance appropriate physical incentives with monitoring and case management activities to discourage excessive or unnecessary displacement of appropriate familial care. And No. 3, the desirability of positive physical incentives, perhaps in the form of tax expenditure policies for utilizing community-based chronic-care systems.

Now, needless to say, much of all this work that we're all here today to talk about will, in the future, fall to existing agencies which, for the most part, are well-suited to their task and have been making efforts in recent years to upgrade their management skills, and they have been doing so in New Jersey with the urging of the Department of Health and with financial support.

In 1979, our alternative systems program in the Department of Health funded for three years a

project to be conducted by Trenton State College, a demonstration designed to meet the management and training needs and strengthen and improve the quality of service provided by New Jersey home-health agencies. The project builds on earlier department-funded efforts to assess the management capabilities of home-health agencies, which really are to be credited with saying that if we were trained as nurses, for example, we did not necessarily learn how to administer, how to do certain kinds of things, how to manage in the very scientific sense of management. I think they're good managers, myself, but they asked really to have their capabilities upgraded, to be ready for the future.

Together with Trenton State College, there has been a study and a design of a curriculum, workshops, seminars, evaluation of these workshops and seminars, and a specific course of study which could form the basis for a competency improvement of present and future home-health agency managers.

Giving a chance for some of your panelists later to respond, I would like to say, going back to my early days before Medicare, that I would like to see the possibility of a plan that was done under my chairmanship at the request of the Department of

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Higher Education, it was done and approved by the State Board of Higher Education, I think it was approved about two-and-a-half years ago, but has not been able to be funded.

I would like to see the implementation of a graduate program in public health in New Jersey. Now, the Trenton State program is fine. It will be placed in a school of business administration. I think, again, it will serve home-health agency managers of the present and future well, but the public health nurses that I knew and worked with me before that I spoke of, which sort of automatically did these things as part of the tradition of public health, home care, were trained in schools of public health where their education was a complete gamut, including good health agency management and administration.

Somehow I think that getting the disciplines back together and mixing the training and epidemiology, the natural history of disease, biostatistics, agency management, and so forth, mental health administrators together with home-health agency administrators together with public-health administrators, I really feel is more productive and so perhaps you will want to ask Chancellor Hollander

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to comment on that. He agrees with me. The efforts, however, in the home-health agency management demonstrations have been successful, and the seminars have been very well-attended. Nearly two-thirds of the forty-seven licensed home-health agencies in New Jersey have already been represented.

Now I'm coming to the end and I'm glad that Governor Byrne came this morning, because he said to you a couple of things, one with which I agree and one with which I do not. He's a nice boss because we can disagree with him. First of all, I do agree emphatically that New Jersey has had a wonderful climate for innovation, for occasionally trying something and fall on my face, I just did last Friday with prenatal regionalization, which was meant to give better care and save money, but so far the State doesn't want it, but it has, it has been a tremendous climate and it has been nice to have two terms. I am sorry that that did not occur in Washington. He also said that he did not think that what you were here for, while he was glad his Cabinet supported you, he didn't think it was politically salable. I don't agree. I would want to give you a couple of hints on how we can work together to make it politically

salable. First of all, as I was listening and I was thinking through my own experiences and I was thinking through the people that I know who are in this room who have had similar problems of trying to get help in the home, trying to get a coordinated well-knit together, keep the family together but let the breadwinner, male or female, continue to go out to work.

I thought that either statewide on some kind of random sampling basis or from some of the various registries, from our Crippled Children's program, from whatever is in the Office of Aging, from the rosters of all of the agencies who are trying to do these things, that we ought to do a survey in New Jersey and we ought to ask, What the hell have you needed that you didn't get? I know what I would answer and I know what Ann would answer and I know what somebody in the back of the room on my staff would answer and so forth. We ought to compile this and ask people, Please be willing to give their names. That is your constituency. You've got to build it, but it's there.

I am sure that there are many, many people that feel the same way I do that are exhausted and who care and will not give up but who just have got

to have a coordinated system out there. Let's try to figure out a way to do this survey and from it, get our constituency because they're there. All we have to do is bring them together.

The second reason I feel that it is politically salable, comprehensive, well-organized, long-term care services including home-health services is because, don't knock cost containment. Let's not. It is very, very fashionable and very, very necessary these days.

I did agree with Dr. Cluff and what he had to say in the period just before you went to lunch. I think together we can absolutely prove that what you're here and gathered about for is saving and helping people at the same time. Now, if we can do that, you've sold three-quarters of a legislature that is just going to have to say, Oh, we're saving the taxpayers money, if and if you do the other part of the survey, your constituency will be there with you.

Good luck.

MS. LIVENGOOD: Thank you. We really appreciate your personal contribution, your address this afternoon. I know how much that meant to you, and thank you very much. We're glad to have

everybody joining in the crusade. We're crusaders, too, so we look forward to a real active next couple of years, and I know Nathan Stark is a crusader, too, or he wouldn't have accomplished all he had. We wish him the best when he goes forth and hope he keeps home-health and long-term care in mind. Maybe you can come back another day and see where we've gotten and give us some more good words.

Thank you, Dr. Finley. We'll now have a ten-minute break.

(There is a recess.)

MS. LIVENGOOD: I'm going to introduce the panel, not in order of how they're going to speak to you, but going from left to right.

The first gentleman is Mr. Herman Hansler. He is here today for Commissioner Sheeran who called this morning and is ill. He really wanted to make it this afternoon, but I guess his doctor said no. He really felt he needed a physician first, and he was going to get up and go. Mr. Hansler has very nicely consented to pinch-hit for him, and I know he knows the issues as well as the commissioner, so we appreciate that.

Next is Dr. Stanley Bergen who is president of the College of Medicine and Dentistry, New Jersey,

well-known and familiar to all of us in the room, I'm sure. We appreciate your time to hear from your lead profession.

Commissioner Ann Klein of the Department of Human Services who has been on the road for all of our clients all fall and we really have been trying to help her in her search for funds, and I know we'll continue to give you that support and hope you get them.

Next is Commissioner T. Edward Hollander, Chancellor of Higher Education, and we are very grateful to have him today, because as we all know, we can't move without the trained personnel, educated professionals that he oversees in the institution that produces these wonderful people we're going to need.

And finally Commissioner Joseph LeFante of the Department of Community Affairs, and we're grateful to you because your Division on Aging has been key lead in much of the long-term and home care. So we'll ask Commissioner LeFante to start.

MR. LE FANTE: Thank you. It's my pleasure to be here today. You know about now, I guess, there's a clock here. You can't see it back ~~here~~,⁺

but we can. I guess about now the great difficulty is staying awake and ~~give~~^{giving} it some thought as to what route you're going to take back home when you leave here and how much traffic you're going to hit and how bad the weather is going to be. I see many of you looking up to the ceiling. What are you looking for, the sprinkler system? That may cool things off a little in here.

I would like to give my remarks by thanking Dr. Joanne Finley for a very candid approach here this afternoon. I was privileged to be in the audience when the doctor was making her presentation and I want to compliment you, Joanne. I think you have a very unique and candid presentation of making everyone feel they're right there with you, and when you share your experiences with us, I think there's a very strong message there. It's a lot better to share your experiences in that procedure than to read a book, and we appreciate it, all the direction that you have given us up until now, and we look forward to some great effort from your department with our assistance in the future.

The representatives on the interagency task force on home-care services from your department and from Human Services and Insurance, and the

Department of Community Affairs will address a number of serious problems. More importantly, they will have finally begun to give home-care services the attention it calls for, and everyone agrees that this action has been long overdue.

I would like to discuss briefly just two things which have a direct and important bearing upon this issue. Both will have a direct impact on long-term planning and in home-health services.

The first is the ongoing process of the White House conference on aging. We have generated nearly six hundred communities forums at which the participants have discussed the very issues in aging that will confront all of us in the 1980's. Over thirty thousand people, that's quite a lot of people if you think about it for a minute, over thirty thousand people, old, young, middle-aged, service providers, consumers, Government agencies, educators, advocates, they've all been part of these informal forums.

We have also involved staff from the Departments of Health and Human Services to hold forums on aging from the point of view of their professional experience, and we have received some excellent material. We've just begun to catalogue

the recommendations coming from all of these people, but it is already evidence that one of the major themes expressed is the need for more long-term care and in-home support services. These recommendations will be an important part of the discussions at the Governor's conference on aging next March, and I am sure they will become part of New Jersey's recommendation for action at the White House conference on aging in Washington next November.

The White House conference on aging in 1961 and '71 have directly generated such legislation as the Older Americans Act, Medicare, the Supplemental Security Income program, and the nutrition project for the elderly. The conferences have had a positive effect on many aging problems, and I feel strongly that the issue of long-term care and in home-health services will be among the priorities for attention and action made by the White House conference.

I also feel confident that the Administration and Congress will support these recommendations, only because it's going to be the most practical way. I think those of us that have been following the news media and some reports as a result of what happened some three weeks ago, that election, agree

that there is going to be a more practical approach taken in the future, and I think what we're trying to put together here with regard to the home-health services is going to prove to be the most practical and beneficial approach, so I couldn't see the Administration or Congress for that matter turning their back on it, and I'm certain that the recommendations are going to gain full support.

The second point I want to make is about a new program directly related to in-home health support. We have started a congregate services program in New Jersey. We are providing homemaker, nutrition, and individually tailored personal services to older persons who need assistance to remain in their own home. I don't have to tell anyone in the field what that means when it comes to retaining the dignity as a human being and your independence as one human to function amongst others, how important that is. In fact, the objective, total overall objective is to keep them in the environment.

Now, at present we're doing this on a pilot basis in seven senior housing facilities, but we are also planning how to add other necessary support services and how to deliver the whole

package in other living environments. Even though this program is only one year old, it is already being acclaimed and requests are coming in from all over the country asking us how to start the service.

Right now members of our Division on Aging and the Housing Finance Agency are at the National Gerontological Society meeting in San Diego presenting this concept to the rest of the country, and I understand in the phone call this morning that it's being extremely well-received. A lot of curiosity is being generated, and the material that they have brought down over to San Diego with them, I understand they've already used it up, so there's requests for additional material that will be sent down from the department.

Once again, it proves that New Jersey has been and will always be the leader in providing service to its elderly and this, again, reaffirms that leadership. Beyond its humanitarian impact, the congregate services program is important in another vital area. It saves money as well as people. That's the practical sense I mentioned before, the practical approach.

The average monthly Medicaid Level B cost of maintaining a resident in a nursing home in 1979-

1980, was \$727. Half of this amount or 363.50 was a cost to the State of New Jersey.

Now, the average monthly rent supplement for a one-bedroom or an efficiency apartment in a subsidized housing project for that same period of '79-'80 was \$330, and that is Federally subsidized, so the '79-'80 average, congregate services subsidy, for an individual was \$75. This \$75 is the total cost to the State for maintaining an elderly person in his or her own home. Compare this to the \$363.50 it costs us to keep a person in a nursing home and you can see that there's a tremendous difference and it would be, we think, a very practical approach.

Not all elderly will avoid nursing-home care, but through a period of time, enough elderly with congregate service's support will postpone nursing homes to affect major savings in the State budget. We should develop this route as quickly and thoroughly as we can.

Now, I deeply hope that this conference will not be just another meeting to clarify issues. We have in the Department of Community Affairs' budget increased congregate services allotment by 100 percent. We had \$100,000 in last year's budget and we've increased it to \$200,000 this year, and

we hope that the Governor of the Administration will see fit to leave it in there, and we have, even though it's still in the pilot stages, we think we're ready to move it into second gear and we're also taking a look at earmarking some funds from our H.F.A. accounts.

There has been some generous surpluses generated as a result of some bonds that have been accumulating interest, and I think we have about \$10.8 million and we're trying to come up with a figure that would be able to tap some of those funds to induce home-health care services and congregate housing into some of the H.F.A. projects, and we're also contemplating somewhere, somehow next year, including home-health care services in some of our bond issue approaches. It's still in the preliminary stages, but we think it's important enough to give it priority. We know the problems. We already have some of the answers. I hope we can impress upon the Cabinet and the policy makers and the administrators that we are in-home support services that are working and that we need their support to continue and expand them while we study ways to improve our delivery and our long-range planning.

I look upon this conference, Joanne, and

the Governor's conference on aging and the White House conference on aging as part of a one-continuing process to develop the total package of in-home health care services and long-term health care planning that our people so sorely need, and we at the Department of Community Affairs pledge our full support to the interagency task force on home-care services and any of the objectives that you discuss here today, so don't feel bashful. We don't want you to be bashful. Call on us any time you may see fit. That's what we're here for, to assist you. Occasionally we like to lean on you for some assistance, too, so as a team and partners, I think we're going to be able to deliver the kinds of services that our citizens deserve.

Thank you so much.

MS. LIVENGOOD: You've been very nice to come and we have a momentum from the Governor for all of our participants. Thank you very much, and we do look forward to cooperating with you and with Mr. Pennestri on long getting aging moneys into long-term care via home-health agencies. Second, I would like to call on Chancellor Hollander from the Department of Higher Education.

CHANCELLOR HOLLANDER: Friends and colleagues, our role in higher education tends to be peripheral. Our responsibility is to assure that you have available to you the variety of required professionals that are necessary in the home-health field.

I'd like to address the question as we are in higher education capable of meeting the demand for whatever personnel you need. Ten years ago I would have said we are not. Ten years ago we lacked a medical school and all of the resource people that a medical school provides for other colleges and universities in the State, and we also lacked programs in some significant fields such as occupational therapy and physical therapy. Today we're very different in our capability. I'm very proud personally of the enormous progress that we've made at our medical school, not just in the education of physicians. That really is a relatively small part of the total operation of the medical school, but in that school's orientation toward community health services and to its broad orientation in public service.

I'm happy to see Dr. Bergen here, and I want to publicly thank him for his splendid

leadership of that medical school, because it has impact on our entire system of higher education with respect to the delivery of health care. I won't pretend that we're fully ready to meet all of your needs, but I can see we have made progress.

First let me state that we don't believe that either the field of home-health care is, itself, an autonomous and independent professional discipline. Rather, we believe that we need to bring within the scope of study in all of the professions that make up the health-care team an element of orientation in home-health care; that is, we need to build upon the professional competence of the nurses and nurse practitioners of occupational therapists, physical therapists, speech therapists, social workers, and any others who are involved in home-health care. We need to provide them with the orientation and the assistance to work with people of all ages in their homes, and many of our programs at our colleges are developing that orientation now.

Secondly, we are deeply involved in an attempt to project the need for persons in the field of health care. We pay a great deal of attention to questions such as how many physicians we need, how many nurses we need, occupational therapists, speech

therapists, and so forth, because the cost of providing those places is so great and therefore we need to have a reasonable, provide a reasonable relationship of our resources to what we think is the expected demand.

I must say, however, that I am convinced after ten or fifteen years in this field that planning to meet career needs at the college level is a very dangerous game if one takes oneself too seriously. Yet one needs it as a starting point in order to build resources in sufficient time to meet those needs.

Let me share with you some of the things we're doing in that area. We have just completed working with the medical school a long-range plan for health-care needs generally. Within the framework of that plan, we've taken a good look at the needs in the nursing profession. I guess that's the most recent data we have available and have found--about six months ago our report was published--have found what we think is likely to be an emerging shortage of registered nurses in this State.

We also did a special study with the support of the Home-Health Assembly of New Jersey about the needs in the home-health care field. We found a

shortage of roughly ninety full-time equivalent nurses, an annual vacancy rate of 9 percent and a turnover rate of 15 percent in the home-health care agencies. We identified what we think is a potential shortage of two-to-three-time equivalent registered nurses over the near term in the State.

Our response has been to invite proposals for two new nursing programs in the State, and we have received those and are in the process of establishing these programs so that we will have roughly ten nursing programs at the baccalaureate level and, as you know, nursing care in the home tends to be offered by nurses who hold a baccalaureate and master's degree. In fact, our outlook for that professional group is very positive at the present time. Roughly one out of four active nurses holds a baccalaureate. We expect that by 1990, roughly 40 percent of all nurses will hold a baccalaureate, and our department is encouraging through upper-division programs as well as through the four-year programs registered nurses to secure the baccalaureate degree in the State. They will provide, we think, a pool of persons available with others in the home-health care field.

In addition to that, there are various

programs under way. We started recently programs in physical therapy Kean College, working with the medical school, a new program in occupational therapy. We are encouraging further programs in both those fields if we can find a college willing to offer them and resource assistance to finance them.

We've also encouraged, and Stan will probably talk about some of the efforts in the fields of gerontology, that are occurring at the medical school as well as some of the State colleges.

Let me close with a suggestion of an approach that I think might be worthy of exploration.

One of my concerns since I've come to the State is the tendency of this State when it gets a good idea to spread it thin; that is, to spread it across the State. There is a tremendous discompensation among our institutions to establish new programs. I think it might be useful to explore the possibility of the medical school working with one of our State colleges which might develop an emphasis in all of its programs that are related to the home-health care team to develop kind of a specialty in that area so that one might have a resource in this State where all of us could look to joining the

medical school and the State college to provide not only personnel in this area, but perhaps even a research capability and training capability as well.

Thank you very, very much.

MS. LIVENGOOD: Those were good words to hear. We need those nurses and that baccalaureate. We're glad to hear that good word. Thank you.

The other member of our panel who was so concerned with our professions is Dr. Stanley Bergen, and we look forward to your words, Dr. Bergen, on the physician and other health professionals.

DR. BERGEN: It's a pleasure to be here this afternoon and discussing with everyone this important subject. I'm sure you're well aware, with the exception of a few outstanding examples, such as Dr. Finley's medical school, was to reserve that the medical schools of our United States have not been known as forward-looking institutions as far as the health-care needs of our State or our United States.

We have not been oriented towards innovative programs; rather we have been oriented towards the in-hospital care. Now, this is understandable when you consider that our faculties

are mostly very super-specialists and therefore need the hospital to practice their particular expertise and even with the advent of family medicine programs at many medical schools across the United States over the last decade, we still have a balance of power in the hands of those faculty members that pursue careers in cardiac surgery, neurosurgery, microsurgery, and other such expertise; therefore, it's unusual to find medical schools that are directed towards the education of their students in modes of health care delivery that might be considered home-care or those parts of home care that would use community agencies and, in fact, learn how to use those community agencies.

As I say, there are some notable exceptions. Western Reserve has been one of them. There's been a program at Cornell under Dr. Reider for a number of years, but interestingly enough, none of these has really caught on with a tremendous spark of interest. Whether that's because the curriculum is already too full, and when you think that in a couple of years, we'll know the whole sequence of the genome, that's the little part on the gene, and we'll know that and supposedly somebody will decide that should be taught to every medical

student in the first or second year, when you consider that a few years ago, two gentlemen by the names of Watson and Crick found out what that double helix did and now every medical student has to learn that, you can see that sometimes the conflicts between the various specialties in a medical school and particularly the scientists and the health-care deliverers lead to the problem of four years is just not enough.

We are, however, I'm happy to say, at the College of Medicine and Dentistry of New Jersey, doing some things in the area of home care and in the area of particularly the treatment of the geriatric patient as a group of patients. Again, though I have to remember the remark made by someone this morning that it's not necessarily brand new, and we may be reinventing, as Dr. Finley noted, because when I was a student a few years ago now, unfortunately, at P & S, we did make home visits with the visiting nurse as part of our educational program, and then when I was a resident at Saint Luke's Hospital in New York, we actually had to go out and make house calls as part of our rotation. Then when I was in Brooklyn, we did have a family health center and worked with a visiting-

nurse service going into the homes out in Bedford Stuyvesant until that became too risky to pursue any longer.

Of course when I was with the Health and Hospital Corporation in New York about a decade ago, we were constantly trying to stimulate interest in home-care programs in all of our sixteen municipal hospitals. It's new and yet it's not new.

Our Office of Consumer Health Education, which Professor Ann Somers, who's sitting right in this room, started, has been very interested in teaching to patients some of the aspects of home care. We've even been such heretics as suggesting self-treatment and even self-diagnosis.

In addition, they've taken great interest in the hospice movement and Audrey Goch, Dr. Goch, and a number of other participants in the Office of Consumer Health Education have given great interest and, in fact, national leadership to the hospice program where, of course, patients with terminal diseases, in most cases, cancer, are cared for at home as long as they can be.

In our Department of Environmental and Community Medicine at the Rutgers Medical School, there is elective whereby students may go out on

home visits with the Visiting Nurse Association. We have a similar program at our Newark school and New Jersey Medical School, and, of course, the osteopathic school in Camden in sponsorship of their area health education center has a very large component of home care as part of that program.

We have involved in nutritional counseling to patients, particularly those who are at home and do not wish to be in an institutional environment, and we have with a Meadowlake Retirement Community in Heightstown, we have arranged for visits of some of our students to the apartments of various individuals who are in that community.

Dr. Somers also provided for us the leadership in developing a series of seminars in geriatrics and the various problems of gerontology and geriatrics, and she has just received word this October along with the Dean of our Rutgers Medical School of the award of a Hartford Foundation Grant, which is a Channelling Grant, again, to utilize existing services within the community, hopefully improve upon those services, and teach our students and residents how to use various options in lieu of hospitalization.

In our Newark school in our program called

the "Health Care Humanities," we've used a slightly different approach in there, a theologian and an ethoist (Phonetic) have joined to run seminars with the students on pointing out the various benefits of home care or more importantly, retaining the patient in the home environment as long as possible. Again, somewhat like the hospice approach, only this time the approach is being made on more of an ethical, moral basis rather than a medical basis alone.

In family medicine, we have an interesting project that we've evaluated extensively, and that is how to teach residents to make house calls. Now, you may all here in the audience think that that's strange, that physicians you would think would come out of medical school, if anything, prepared to make house calls, at least for the first six months, because that would be a way to make a little extra money and keep the wolf away from the door and pay the rent and buy the equipment. Many medical schools have never, to this day, taught one of their students or residents or anyone how to make a house call, and there is an art to making a house call. I can say that from personal experience, having been in practice as a general internist, family physician

for a few years, and there is an art to making a house call, so it's long enough to take care of the patient, the family, and everybody else, yet not so it becomes a burden to them or a burden to you.

We find it becomes about two years to teach a resident how to make house calls. That seems kind of ridiculous, doesn't it? In order for them to absorb the teaching of their mentors, in order for them to become self-sufficient and make adequate house calls, it takes them about to the second year of their residency. There's a fallacy, too, that there are not house calls made by physicians in New Jersey. When we began studying this problem, we found out that physicians in New Jersey, if you exclude the hospital-based physicians, those who are based in a hospital for a particular reason that they give a service that needs a hospital facility, you have about 80 percent of the physicians in New Jersey being non-hospital-based, and they make on an average of six house calls a week. About five of those house calls are scheduled house calls. In other words, their patients who they know and patients that they have taken care of and patients that need their ongoing continuing care, and about a little over one house call a week is

made on an emergency basis.

The people seen on these house calls are usually elderly, home-bound individuals, most often with stroke or cancer or some terminal illness, congestive heart failure, and for the most part, these house calls are planned.

Another fallacy is that people need to see a physician. We were chatting about this a little bit at lunch. When I was in practice, I found that one of the major problems on house calls was convincing the patient they didn't need to see me, that somebody else, in fact, could do a much better job. Using the visiting-nurse service, using physical therapy personnel, using home makers to go into the home often was much more productive for the patient and much more important for them, but it was surprising how hard it was to convince both the patient and often, more importantly, the family, that someone else could do this house call better and be more productive and gain a greater end point for the patient than the physician could.

Now, one project that we're looking into right now which has some interest to me, certainly, I guess just because of my curiosity about it, is a warning system. This has been tried in Boston.

There are a group of hospitals in the Boston area that have tried this, and one or two other places in the United States are contemplating this. It's usually set up through a hospital, and there's a switchboard light in the telephone operator's area, and twice a day the group of patients or clients that are hooked up to this system merely activate a bell or a buzzer in their home that they can hear or a light goes on so they can verify it's working and that puts the light on in the switchboard of the hospital telephone room, and if the operator checks this at ten o'clock in the morning or ten-thirty and sees that Mrs. Smith's light is not on, then she has a contact person to call. If that contact person is unavailable, then a home-health aide is sent to the home to see if maybe this person fell, maybe this person is sick and in bed and unable to get out. The same thing usually occurs again at about four o'clock in the afternoon.

Assemblyman Schwartz is very interested in working with us in the Middlesex County area to try to develop such a system based within the Middlesex General Hospital. It certainly seems to me it would be a worthwhile trial, at least for New Jersey, and see how it works here.

Lastly, I would just like to make a few comments or recommendations. You've certainly heard more than adequately about the reimbursement system. It has to be an incentive system, or else it unfortunately will merely be an add-on. We've done so much of that in this country over the years. In some way, some clever person, not me, has to figure out how we can get some trade-offs out of the system for a change and particularly, I think, this area should lend itself very nicely to such trade-offs, some kind of reward system, both for the participant, the patient, and also for those who are rendering the services where there would be some incentive to use home-care services and develop a structure of health care that would be fundable and reimbursable on all levels, and that's my second recommendation.

We can't continue a system that merely funds physicians and in some cases nurses and in some cases physical therapists, but it has to be a system that funds all levels of care, whether that's rendered by a home-health aide or by some other types of support personnel.

You've heard before, and I repeat just to emphasize, we need the team approach. As I noted,

a physician is not always the most efficient, even the best-educated person to make home-health calls, and certainly we need to use other types of expertise.

I like the Chancellor's idea of maybe working with a State college to develop some kind of a comprehensive program of training the whole team of individuals. We need support services; by that I mean we need a nutritional program that's adequate, shopping services. This contact system that I noted before is attractive to me, and as I said, any of these systems has to have a built-in incentive to it and some type of trade-off.

And lastly, I'd just like to make one personal note, and that is I think we have to make it an element of pride. Somehow this country has lost the pride of caring for its older people, and I mean that not in the institutions, but at home. I don't know how we do that, but somehow we have to restore to the family the pride of keeping the former generation at home with the current generation and the future generations. I think there's a great benefit to that kind of structure. I know personally, again, like Dr. Finley, that last Christmastime both my parents-in-law had sustained strokes at the

same time. I think it was the most pleasurable experience of our Christmastime in our family to have both of them at home in our home for the first time ever living there and see them rehabilitated and come around to where finally after about four weeks with us they were able to move back to their own home. I think the children enjoyed it immensely on giving services to their grandparents and providing support and also learning not to provide too much support on encouraging them to become independent again.

I think the experience was not only heartwarming for all of us but very productive for all of us. It taught us a different aspect of health care than we had known before, so I think somehow while it is an obligation and should be recognized as that by each family, somehow we have to restore that to an element of pride within our families that we want to care for the older people of our country and we want to care for them where they benefit the most and where they can also benefit us.

Thank you very much.

MS. LIVENGOD: Thank you, Dr. Bergen.
That was a really helpful and instructive speech,

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and I'm sure a lot of us are ready to support what the College of Medicine and Dentistry is doing.

Ann Klein, Commissioner of Human Services, you're next. We look forward to what you have to tell us.

MS. KLEIN: I must say I enjoyed listening to the other speakers, and I'm not sure that I have anything much to add to everything that's been said, but I'll find a way to do it.

In case any of you saw the Star Ledger this morning, we do not have \$40 million in unpaid bills. We will have \$40 million in unpaid bills if we don't have a supplement to the Medicaid budget or if we don't trim back the program the way we have put in the register. The last thing in the world we want to do is that. Just to clarify that, I do want to make that point.

It seems to me that our society is confronted by two forces moving along on a coalition course, and this has really been taken directly from several paragraphs that we included in our Channelling proposal. One force is the growing number of people who require substantial assistance from Government because of amount of disability, and

the second force is the relatively stable portion of the population capable of producing goods, services, and tax revenues necessary to assist the dependent group.

I'd like to interject in that I think one of the things we're going to have to do as we start thinking about the aging population and the increased life span and how to provide services is I think we're going to have to change our standard for when you start to age. Maybe having President Reagan will accomplish that for us. At least he's shown that a man almost seventy is capable of running for President. Now we'll find out if he's capable of being President. I thought it was kind of heartwarming to see--not that I was one of his greatest fans, I still think there's something to be said for this image-- You don't have to curl up and start getting free transportation and everything else when you've sixty-five years old. You may still be able to live a little longer and enjoy life.

I am constantly amazed by the numbers of people quite on in age. It seems more the older I get, the more wonderful it seems, who are out there just really participating and very, very alive and making enormous contributions, and I'm constantly

surprised sometimes what the age is of some of the people I've seen and worked with. I've seen people retire from State service and we place incentives into retirement. If they don't retire by the time they're seventy, they lose a lot of pension benefits, particularly for their dependents, and so we really shove people into retirement who really still have a great deal to contribute.

I think as the proportion of the population changes, and right now we've got 5.4 non-elderly to one elderly, and by 1985, we're supposed to have 4.9 non-elderly to one elderly. This is over sixty-five. That ratio is going to continue to increase. In other words, the proportion of the elderly is going to increase as we go on into the '80's and '90's. Maybe more significant, the proportion of the "old old" and the ones who are over sixty-five will increase even faster than the young old, which is the sixty-six to seventy-four. So today 38 percent of the elderly are seventy-five and over, and by the year 2,000, we expect 45 percent of the elderly will be over seventy-five. Between '80, 1980 and the year 2,000, the proportion of minority elderly is expected to rise by 60 percent, which is really a lot compared to 30 percent for the total.

It will be expected to rise 60 percent compared to 30 percent for the total over-sixty-five population, so that the percentage of minority elderly will increase and that, I think, is testimony to what has happened to health care for poor people.

It shows that something is working, Medicare, Medicaid, and so forth is having an impact. We are going to be dealing with increasingly large populations of people over sixty-five and particularly over seventy-five, and I think one of the things we have to do is keep everybody out there working and active and participating as long as we can, and that, I think, is really the thrust of this conference also. Let's keep people in the home. It means more than let's have doctors and nurses to go visit people at home. That can be very expensive. It means, I think, a whole philosophy about the health care and social care and treatment of the elderly, so that people remain alive and well and not sink into the kinds of depressions that are so commonly associated with old age and which lead to debilitation. We've seen it certainly in our institutions where people have been institutionalized for years and years and they have lost really the will to live or the ability to make decisions.

They live a long time. We give them lots of care. Lots of them are over the age of ninety. The life has gone out of them long ago, and it takes a great deal to try to rehabilitate them once that has happened.

Now, elderly population is estimated now at 854,000 people, and I think I can vouch for that. We have almost 278,000, and I think that's the figure. Such people on the pharmaceutical assistance to the elderly and, of course, they are also eligible for the Lifeline Program. Now, that program is limited to people with incomes under \$9,000 or couples with incomes under \$12,000, so that shows you that out of these 854,000, not counting the Medicaid population and the S.S.I. population, we have almost 300,000 people in that relatively low-income bracket, but it becomes more significant, I think, when you look at the figures which we recently developed which shows that half of the people on the P.A.A. program have incomes under \$5,000, and we found quite a few from that program who were actually eligible for S.S.I. and had not been receiving it. So there are literally hundreds of thousands of people over the age of sixty-five on very, very limited income and this,

I think, is a very high contributor to disability.

I don't know how people do it. I really don't know how they manage to find any kind of decent housing in which to live, and the answer is that a lot of them don't. How they manage with food stamps to provide enough food for themselves, I don't know. True, they do get Medicaid.

I want to say something about the Medicaid program. The big problem, and I'm sure it's been discussed before here today, although I wasn't here to hear it, is that we can only provide Medicaid for people whose income is above the very, very minimum of Welfare and S.S.I. to people who are institutionalized. You can have an income, I guess, up to almost \$700 a month and be on the Medicaid program if you're in a nursing home or in a psychiatric hospital if you're over sixty-five. That means, of course, that you've exposed of your assets or used them up and you are contributing from your own income toward the cost of your care and you are only allowed to keep \$25 for your personal needs. Then we will pay the difference between your income and what the nursing home costs.

There are a lot of people who are in Medicaid nursing beds on that basis who did not

necessarily get in there because they were on Welfare and S.S.I, but who have limited income which makes them eligible for Medicaid if they're in a nursing home.

In fact, sometimes I really wonder what's happening to the S.S.I. and Welfare recipients, whether, in fact, they are getting into these nursing homes, because the way to get in very frequently is by getting in as a private patient, using up your assets, and then remaining as a Medicaid patient. There are exceptions to that, but we are serving a much broader eligibility in nursing homes than the usual patient who is receiving Medicaid assistance.

Now, irony is that those same people cannot be helped by us for partial-hospitalization programs, day care, or for home-health services. There are two ways to solve that, of course. One would be for New Jersey to get a medically indigent program or medically needy program which we in the Department have been strenuously supporting and have put bills out every six months, but you know what happens. It costs money, and so far we haven't been able to do it. I hope that the casino revenues will be amended so that revenues from

casinos can be used for health-care services for the elderly, certainly for additional health-care services for the elderly. It is one of the fastest-growing costs that we have in Government.

We're going to need a source of revenue that grows. It's all right to give the gasoline tax, I suppose, to the highways, although I'm not in favor of dedicated funds, but if we're going to go that route, I want some dedicated funds for this purpose. The other way to solve it, of course, would be for the Federal Government to change its law, and I guess one of these bills, I think the House bill, is directed in that direction so that people would be eligible for home-health care at a same standard that they're eligible for nursing care.

I think that although I really do want to join in with everybody about how cost effectiveness will be and how much money we will save by providing home-health care instead of home care, I do have to say that I think it will be more expensive in the aggregate. There's no question in my mind that it is a better cost of care and that the quality of life will vastly be improved for many, many people out there who aren't getting any kind of care.

At the same time, I think we have to recognize that those nursing home beds are not going to become empty. We are going to continue to need them. Commissioner Finley pointed out that 33 percent of those patients who are in level I.C.F.B., 35 percent, found that they could live outside of a nursing home if they had an alternative, but we have to realize that I.C.F.B. level is only 30 percent of the total numbers in nursing homes. We're really talking about 10 percent of the nursing home population is what we found in the Medicaid study of Medicaid patients who could be served in some alternative. I think it's important to know that the average age in our Medicaid beds is eighty-two, and when you think about that, you realize that their youngest child, that means a lot of people over eighty-two, and we're talking about family care with people whose youngest child is sixty-five and may be needing home-health care herself.

I would like to say that we would like very much to be able to do something more to expand home-health care, partial hospitalization, and day-care programs. We think they're tremendously important and fruitful.

We wanted to change the Medicaid home-

health care manual so that we could include expanded personal-care services as part of the services eligible for Medicaid, and people have talked today about how and why that is an important direction to go. Actually we had it all ready to go in the register. I was counting on it that we were going to get the change in the Constitution, have some casino funds available, and that this was the direction we would be able to go and pay for out of casino revenues. That didn't happen.

Now, it isn't a terribly expensive thing. It would only, again, serve those who are eligible for Medicaid in the community, which is a relatively small part of the need, but nevertheless, it would have cost \$2 billion in State money and we had to hold off on it and we certainly, at a time when we are threatening, and I don't mean threatening, I mean promise. We have no choice. We are going to have to cut out every non-mandated Medicaid service in February if we do not get a supplement to the Medicaid budget. We have no choice on it.

It is terrible to think that we will be eliminating from the Medicaid program all pharmacies, all crutches, home-health aides, things that people need who are disabled, teeth, eyeglasses, things

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that keep people healthy. It is a really incredible direction for a state to take, and yet we don't have the choice because our services--we are limited by the mandates from the Federal Government. We're already paying providers for ambulatory service, only 50 percent of the customary fee. We really can't go in the direction of cutting that anymore.

As I see it, I am extremely hopeful that the rate-setting program is going to result in long-term benefits in terms of cost containment, but for the moment, at least, it is a very good way to help hospitals pay for part of their indigent costs. It brings the Federal Government into that picture, and it cost more money in the Medicaid budget.

We have a very serious problem to face. We would like to do all of these things. We would like to expand our present manuals to include whatever home-health care services we can. We would like to expand day-care programs and partial hospitalizations. We are very supportive of bills that will expand eligibility, but we would have to insist that that be accompanied with additional Federal participation, and the bill that calls for an additional 25 percent of Federal participation is a good thrust in that direction. It certainly

sets a priority.

I would like to see a 25-percent increase in Federal participation in the whole Medicaid program, and I would like to see Medicare, which is a total Federal program, expanded to include some of the very necessary services, including home-health care, and including some nursing care and including some pharmacies, necessary life-sustaining pharmacies, so that, in fact, the State could be relieved of some of that economic burden.

I think I talked too long. Thank you.

MS. LIVENGOOD: We do want to thank you. We've lobbied intensely with you, and as providers in the Assembly, we will continue to do so. Thank you.

Herman Hansler from the Department of Insurance which is a particularly sensitive issue for home health, insurance coverage of all types, but particularly commercial insurance, and I hope maybe you're bringing us some comments on insurance requirements.

MR. HANSLER: Thank you. I will do my best to be brief.

Patient home-health care participants,

you've been listening for a long time and so have I. I've learned a great deal and I know you have, too. It's a program that was well-designed, and hopefully it will bring some real concrete productive results in the future.

Early this morning, I spoke with Commissioner Sheeran who very much wanted to be part of this program, but because of an illness, he is unable to be here with us. It is, indeed, ironic that the Commissioner is home ill on the very day that he was to have served as a panelist on home-health care. One never knows when the need for home-health care will directly apply to us as individuals. It should be noted, however, that it is not necessarily because he is confined to his home with an illness that Commissioner Sheeran is in favor of the home-health care concept as a means of containing medical-care costs.

Not only do we have the opportunity to save the difference in claims costs between a home-health service and a more-expensive traditional form of health care, but we will also save the costs associated with the insurance mechanism that will be attributed to health-care costs containment; therefore, in a case of commercial insurance

contracts, insureds could benefit to the extent of 130 percent or more of any actual savings effected through cost containment of any type.

Commissioner Sheeran is committed to promoting cost containment in all forms of insurance, and since the claim cost represents the greatest potential for savings in the insurance premium dollar, he is anxious to work with the Department of Health and other agencies to cut health-care costs.

We currently provide input through the Hospital Rate Setting Commission and the Health-Care Administration Board, and we stand ready to work with the Department of Health, Department of Human Services, and the Department of Community Affairs on the newly created interagency task force on health-care services.

I wish to publicly commend Dr. Finley and her staff and all the other agencies and departments that are involved for their leadership in promoting alternative means of health care in New Jersey

Thank you.

MS. LIVENGOOD: Thank you so much.

We do have our three distinguished visitors from Washington today, and I think I'll

call on Letitia Chambers and she will come up and give us a brief report from Washington and perhaps a roundup of the issues that came out today. We may not have to hear from her about Channelling or Medicaid differentials.

MS. CHAMBERS: First I want to congratulate the State of New Jersey for convening this excellent conference, and I do want to mention to you that at the close of yesterday's hearing, which was convened jointly by the Senate Committee on Labor and Human Resources which is chaired by Senator Williams and by the Senate's Special Committee on Aging on which Senator Bradley now serves and which, incidently, was created by Senator Williams a number of years ago in the Senate, at the close of that conference, Senator Williams did announce that the record of that hearing would remain open and all of the contributions in today's conference will be made a part of that record.

I believe that this conference will thus make a great contribution to national efforts and national debate to solve the dilemma of a fragmented home-health system and the need for a long-term care system that's comprehensive and that includes health

and social services.

I do have some news from Washington. In the past week, Congress has approved amendments to the Medicare program under the 1980 Budget Reconciliation Bill. Now, Budget Reconciliation was meant to be a money-saving bill, and various committees were directed by the Budget Committee to come up with savings in entitlement programs.

The Finance Committee which has jurisdiction over Medicare and Medicaid came up with savings in some programs but with some new costs in other programs and attached it to the Reconciliation Bill. Interestingly enough, those survived the reconciliation conference and will, if accepted by both Houses, the conference has reported the Houses have not yet voted on the conference report, but passage is expected. If the President signs them, these things will become law.

One is that the legislation will permit an unlimited number of home-health visits per year under Parts A and B of the Medicare program. Two, the amendments eliminate the three-day-prior hospitalization requirement under Part A. Three, they eliminate the \$60 deductible provision for home-health under Part B. And four, the bill will

require Stage 2 to provide approved training programs for home-health aides. So this is a substantial achievement, I believe, in progress. They had to take something out in order to make up for these increases, but I think this may answer the question "Is home-health care salable?" because home-health care in about a \$7 billion reduction bill, home-health care was the only issue that received increases.

I would like to make just one very brief point in closing. About a third of the Federal budget is now spent on the elderly and disabled. That's through pension programs, Social Security, S.S.I., Medicare and Medicaid, and the portion of the various social-service programs that are devoted to programs for the elderly. Third of the budget, that's a substantial amount.

Now, Commissioner Klein gave you some ratios of population of how many people we have now per elderly person in the country. I'd like to give you another ratio that's in line with those consistent with that, but I think more revealing, and that is that very soon in the course of about two decades, we're going to have less than three workers in this country per retired person, less

than three people. Between two and three persons per retired persons. That means those people who are producing compared to who must support those who have left the productive section of our society. That's a very monumental change.

Two decades ago, I think it was something like eight workers per each retired person, so you see what's happening as the population ages. The implications of this are mind-boggling. The size of Social Security and other income maintenance programs, the size of Medicare and Medicaid, the scope of the need for social services is going to be beyond what you're envisioning today without question. The resources are going to be, if anything, less. I don't mean immediate budget resources, but I mean within the economy the number of productive-to-non-productive persons is going to be less, so we're going to have a major issue.

I think that the issue of how to deal with an aging population, a smaller work force in relation to its retired population, is going to replace energy as the most pressing crisis in our country. I think that the work you're doing here in working toward long-term care policy is of great, great importance, but I think it has to be looked at

in this overall spectrum and the implication for Federal policy as a whole, and I believe that we'll see solutions over the next two decades to this problem if we continue to convene the creative people around the country who are doing the work such as you're doing here.

Thank you.

MS. LIVENGOOD: How's that for timing?

It's four o'clock. Adjournment is called for.

Thank you all for coming, for your contribution just being here today, and thanks to our panelists, one and all.

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The CHAIRMAN. The hearing stands adjourned.
[Whereupon, at 4:40 p.m. the committee adjourned.]

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