

HEALTH CARE FOR OLDER AMERICANS: THE "ALTERNATIVES" ISSUE

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BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
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Health Care for Older Americans: The "Alternatives" Issue:

- Part 1. Washington, D.C., May 16, 1977.
- Part 2. Washington, D.C., May 17, 1977.
- Part 3. Washington, D.C., June 15, 1977.
- Part 4. Cleveland, Ohio, July 6, 1977.
- Part 5. Washington, D.C., September 21, 1977.

(Additional hearings anticipated but not scheduled at time of this printing.)

CONTENTS

	Page
Opening statement by Senator Frank Church, chairman.....	1
Statement by Senator Lawton Chiles, presiding.....	3
Statement by Senator Pete V. Domenici.....	5
Statement by Hon. William Cohen, a Representative in Congress from the State of Maine.....	7
Statement by Senator Spark Matsunaga.....	8
Statement by Senator Charles H. Percy.....	43

CHRONOLOGICAL LIST OF WITNESSES

Wennlund, Dolores M., R.N., M.S., public health nursing program supervisor, Department of Health and Rehabilitative Services, State of Florida.....	9
Friess, Constance, M.D., New York, N.Y.....	14
Kinoy, Susan K., associate executive director for program services, Community Council of Greater New York, New York City.....	19
Walden, Judith, R.N., director, Hospital Home Health Care, Albuquerque, N. Mex.....	23
Liversidge, Robert P., Jr., executive director, Bath-Brunswick Regional Health Agency, Bath, Maine.....	33
Breslow, Ruth W., Rockville, Md., executive director, Jewish Council for the Aging of Greater Washington.....	37
Robins, Edith, Deputy Director, Division of Long-Term Care, Health Resources Administration, Department of Health, Education, and Welfare.....	55

APPENDIXES

Appendix 1. Letter and statement submitted by Senator Church:	
Item 1. Letter and enclosure from JoAnna DeMeyer, project director, and Jane Runyan, project codirector, St. Luke's Hospital, Boise, Idaho, to Senator Frank Church, dated August 23, 1976.....	59
Item 2. Statement presented by Larry M. Belmont, director, Home Health Services of the Panhandle Health District, Coeur d'Alene, Idaho, before the Subcommittee on Health and Long-Term Care of the House Select Committee on Aging, February 24, 1976.....	60
Appendix 2. Additional statements and letters:	
Item 1. Letter from Dolores M. Wennlund, R.N., M.S., public health nursing program supervisor, Health Program Office, Florida Department of Health and Rehabilitative Services, Tallahassee, Fla., to Senator Lawton Chiles, dated May 25, 1977.....	71
Item 2. Letter and enclosure from William L. Gee, president, and Marie-Louise Ansak, executive director, On Lok Senior Health Services, San Francisco, Calif., to William E. Oriol, staff director, Senate Committee on Aging, dated February 15, 1977.....	71
Item 3. Letter and enclosures from Herbert Shore, Ed. D., executive vice president, The Dallas (Tex.) Home for Jewish Aged, to Senator Lawton Chiles, dated May 29, 1977.....	73
Item 4. Letter and enclosure from R. E. Rosenberg, vice president, planning and development, Homemakers Home and Health Care Services, Kalamazoo, Mich., to Senator Frank Church, dated June 15, 1977.....	83
Item 5. Letter and enclosures from George L. Maddox, Ph. D., director, Center for the Study of Aging and Human Development, Durham, N.C., to William E. Oriol, staff director, Senate Committee on Aging, dated May 13, 1977.....	100

Item 6. Correspondence between Louise M. Biggs, Salmon, Idaho, and Senator Frank Church.....	117
Item 7. Statement of the day hospital, Burke Rehabilitation Center, White Plains, N.Y.....	119
Item 8. Statement of Louise Woerner, vice president, J. A. Reyes As- sociates, Inc., Washington, D.C.....	125
Appendix 3. Charts: Eligibility for "alternatives" in four Federal programs	130

HEALTH CARE FOR OLDER AMERICANS: THE "ALTERNATIVES" ISSUE

MONDAY, MAY 16, 1977

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, D.C.

The committee met, pursuant to call, at 10:08 a.m., in room 6226, Dirksen Senate Office Building, Hon. Lawton Chiles, presiding.

Present: Senators Church, Chiles, Domenici, and Percy; and Representative William S. Cohen.

Also present: William E. Oriol, staff director; Kathleen M. Deignan, professional staff member; Caroleen L. Silver, minority staff director; David A. Rust, minority professional staff member; Alison Case, assistant chief clerk; Catherine A. Sehler, resource assistant; and Eugene R. Cummings, printing assistant.

OPENING STATEMENT BY SENATOR FRANK CHURCH, CHAIRMAN

Senator CHURCH. The hearing will please come to order.

My statement for this timely hearing can be summed up with one question: If costly hospital and nursing home care is inappropriate for many older persons who need sustained but not full-time attention in an institution, where are such persons to turn for help?

The standard reply to that question, particularly since the White House Conference on Aging in 1971, has been that alternatives to institutional care must be developed, and among those alternatives should be home health care, home help and chore service, adult day centers for regular drop-in help, hospital-based outpatient facilities, meals-on-wheels, sheltered housing, and combinations of all these possibilities.

I have some quarrel with the use of the word "alternatives," and I hope that these hearings will make the point that often there can be no substitute for the nursing home or the hospital for people who need the staff and daily routine which only an institution can provide.

I tend to agree with the consultant to this committee who recently wrote:

The use of the term "alternatives to institutional care" to describe a relatively small number of community approaches is unfortunate since it seems to imply either/or solutions with, more often than not, an implied rationale based entirely on economic considerations.

In other words, we have to develop community based systems in which there is a role for institutions and a role for other forms of help, provided when people need it, in the home or elsewhere.

Now this is hardly a remarkable conclusion. For years now, at hearings before the Senate Committee on Aging, I have heard directly from older persons who tell me emphatically that they don't need an institution, but from time to time they may need assistance in maintaining their independence in order to stay in their own homes. There is no doubt that home health services would be popular among older persons who need them and there is no doubt, either, that they still remain widely unavailable.

The number of home health agencies in the United States continues to decline at just the time that they should be increasing. Even my legislation for startup funds for such projects provides only limited help when much more is needed. At the root of the problem, of course, are restrictive medicare and medicaid policies on in-home services. I introduced legislation last year to deal with that problem, and I will consider its reintroduction this year as soon as I analyze recommendations made at these hearings.

Another problem which becomes more apparent with each passing month is that home health and other noninstitutional sources of help and care are suffering from fragmented funding.

Limited as they are, medicare and medicaid do provide some support. So does title XX, the social services program. And so does the Older Americans Act, as mandated by the Congress. Each source, however, has differing requirements and each is underfunded.

CBO ESTIMATES OF NEED

The Congressional Budget Office summed up the situation well earlier this year when it said that an estimated 800,000 to 1.4 million disabled persons of all age groups may receive no form of long-term care, even while, at the same time, there is evidence that 20 to 40 percent of the nursing home population could be cared for on less intensive levels were adequate community based care available.

When do we start providing such care, not only for those who don't belong in institutions, but for many homebound persons who somehow get by even when help from families and neighbors is not available?

That question should be asked, and dealt with, fairly early by the current administration.

President Carter has already made it clear that he wants hospitals to cut costs. I would think, too, that he would want to assure older Americans that they can obtain help tailored for their individual needs, which will enable them to live independently as long as possible, even when affected by one or more chronic illnesses.

I will, therefore, be especially interested in testimony by HEW officials and I will look for indications that they intend to move toward making noninstitutional options more readily available.

I will also ask for HEW views on ways to encourage application of a discharge planning program that is now in effect, as it happens, in my own hometown in Boise at the St. Luke's Hospital. Given help from the Western Interstate Commission for Higher Education, the St. Luke's staff has designed a model concerned with those patients who no longer need skilled nursing care and who could be supported in more independent living situations. Significant cost savings have been reported but, more important, the patients feel more in control of their own existences.

I submit for this hearing record a letter¹ written to me last year from the project directors. I also submit an excellent statement² from Larry M. Belmont, the director of Panhandle District I in Coeur d'Alene, Idaho, who gives an excellent account of the successful home care provided in a predominantly rural area.

Now I want to express, as the chairman of this committee, my special appreciation to Senator Chiles, who has had a very keen interest in this question. He has looked into it before and conducted hearings in his own State and elsewhere and has agreed to preside at these particular hearings. I want to thank him for that and tell him that I am due to testify at other hearings within a few minutes, but I appreciate the fact that he has taken over here. I will be back as time permits to give him such assistance as I can, but I am certainly going to look at the whole record. We hope that this record will help us move the home care programs along and make them a more significant part of the health care offered through the Federal Government.

I want to thank the members of the panel and the other witnesses who will appear here this morning.

With that, Senator Chiles, I turn the hearing over to you.

STATEMENT BY SENATOR LAWTON CHILES, PRESIDING

Senator CHILES. Thank you, Mr. Chairman. We are delighted with your opening statement and to have the leadership that you provide for us in this area.

As it has on several occasions in the past, the Senate Committee on Aging is seeking today to update information on what are so often called alternatives to institutional care. We have, over the last 5 or 6 years, sought to obtain the latest ideas and details on such matters as home health care, other forms of in-home service, and day service in adult centers or outpatient facilities.

We began by focusing on home health care, and I think we made the case, very conclusively, that there is a bias against such care in medicare and medicaid. We spend billions of dollars for hospital and nursing home care in this country, but precious little for help outside those institutions. The latest figures, in fact, indicate that medicare still devotes only 1 percent of total expenditures to home health care, and in medicaid the proportion is even less.

The committee has also looked into the potential of adult day facilities as a means of providing services in a group setting while allowing older persons to live independently in their own homes. And we have tried to take the positive viewpoint that noninstitutional care can be less costly than care in nursing homes and hospitals. At least equally important is the kind of care that most people want and need, unless it is absolutely essential that they receive full-time institutional care.

FACING HARD FACTS

But we have also had to face hard facts. We have expressed our concern about the spread of for-profit home health agencies under several federally supported programs, not because we are against profits but because we worry about shortcomings in accountability. And just a

¹ See appendix 1, item 1, p. 59.

² See appendix 1, item 2, p. 60.

few months ago we looked in some detail at the operations of a California home health agency accused of using highly questionable tactics in its use of public funds.

This investigation followed one that I made for the Government Operations Committee in Florida last year. Again, the question was the lack of accountability—this time in “medicare only” home health agencies which have proliferated remarkably in that State. I have made several recommendations for corrective action. When HEW witnesses appear later, I intend to ask whether any progress is being made.

In my State, I found a fellow who had been a school teacher; the highest salary he had obtained in that profession was some \$14,000 or \$15,000 a year. He opened a not-for-profit institution and paid himself \$30,000; he paid his wife \$20,000; he paid a daughter \$10,000; and his visiting nurses got \$35 a visit, while the Visiting Nurses Association, which had been in operation some 15 or 20 years, was getting \$14 a visit—all under a not-for-profit or a nonprofit institution.

And so this committee has seen both the promise and the problems which arise when Federal programs attempt to pay for services outside the institution. Just as we have observed skyrocketing costs in hospitals and fraud and abuse within the nursing home and some boarding homes, so do we find them among the so-called alternatives. Waste and wrongdoing is, therefore, very much on our minds as we attempt to obtain the final facts we need before issuing a report on the alternatives issue.

We are concerned about other issues as well. In fact, 5 years after the 1971 White House Conference on Aging where so much was said about the need for alternatives, we can even ask whether we are making any real progress in providing them. As I have already indicated, medicare and medicaid give scant encouragement to development of non-institutional care.

It could be said, however, that since the 1971 conference other funding sources have emerged. The title XX social service program under the Social Security Act is now helping pay the bill for some alternatives care. The Older Americans Act has been mandated by the Congress to make home health a priority matter. But the increase in the programs involved has also resulted in fragmented funding, widely varying eligibility requirements, and a great deal of confusion.

ACCOUNTABILITY REQUIREMENTS MINIMIZED

So in the rush to satisfy the demand for alternatives, accountability requirements seem to have been minimized in some cases. Today and tomorrow, we will hear from witnesses who can tell us something about the individual-provider approach to providing home health care. It seems that vulnerable and frail older persons in need of such care make their own arrangements to receive it from a self-employed or freelance provider who may or may not be trained. The opportunities for poor care and even fraud are obvious. The possibilities for abuse of the patient—and the provider—are numerous. If Federal funds are used to pay for such arrangements, shouldn't there also be a Federal responsibility to see that they are effective, humane, and cost-controlled? This is another question for HEW.

I will close by saying that we have made a point of inviting witnesses

who can talk about successes—or potential successes—in providing alternatives. I congratulate them for the ingenuity and their perseverance, but I think that they are laboring against great difficulties which should receive attention from the Congress and from the executive branch.

This is particularly true at a time when a new administration begins to dig deeply into many issues which were put on the shelf by its immediate predecessors. Heavy emphasis is being put on reorganization and upon the need to judge objectively the effectiveness of programs. The HEW reorganization, which calls for a new Health Care Financing Administration, with responsibility for medicare and medicaid, could be constructive if it finally ends the divided administration over these two programs. But will the new Health Care Financing Administration also bear responsibility not only for reimbursement of institutional care but for all the other forms of care that an increasingly aging population will require? That is another question for HEW. If answers are not readily available, this committee will certainly work together with HEW to make certain they are forthcoming.

We are delighted to have with us today, representing the House Select Committee on Aging, Congressman Bill Cohen from Maine, who has long had an interest in this program. We are going to see if he has a statement, but before I call on him I would like to call on Senator Domenici from New Mexico, the ranking Republican member of this committee who has done valuable work on this question, for any opening remarks that he might have.

STATEMENT BY SENATOR PETE V. DOMENICI

Senator DOMENICI. I thank you, Mr. Chairman.

I will be brief. I wish to commend you for your opening remarks. I, too, have been a strong advocate of finding alternative ways of delivering health care. I visited two such institutions in my State, one run by a combination of hospitals and one run by a nonprofit organization. I was impressed by what I saw.

I find it difficult to believe that we are at this point in our history and have not made a serious impact on this problem. When we look at the amount of money we are spending for health care, in particular for the elderly, we find that such a small amount of it is being used in home care that it makes this particular hearing very important. When we talk about new approaches to helping our people with health care it is very important to focus attention on the need to develop an effective delivery system. We have a witness from New Mexico, Judy Walden, who is part of a success story.

I do hope, Mr. Chairman, that consistent with our new approach this year we end these hearings with a positive commitment by this committee to have a direct impact on our authorizing committees in the Senate. We want to move ahead and not just continue to hold hearings on these problems. Collectively we should put pressure on our authorizing committees to begin solving the problems that obviously exist. Home care is in its infancy. It has a tremendous potential as part of a total health system for our people. I commend you, Mr. Chairman, for your past efforts and for convening today's hearing.

[The prepared statement of Senator Pete V. Domenici follows:]

PREPARED STATEMENT OF SENATOR PETE V. DOMENICI

As we address the issue of alternatives to institutionalization, our prime concern should be the wishes of the older persons themselves. The desire to remain independent is a compelling force in the lives of the elderly, and should be reinforced by whatever methods we can devise.

The provision of supporting services to the home, whether they be health services or assistance with personal needs such as cooking, shopping, transportation, and personal care, is one of my highest priorities. It is discouraging for me to realize that many of the problems which were discussed at the hearings I held in Albuquerque and Santa Fe in New Mexico in May of 1974 still exist today. The delivery of home services has not been measurably increased, despite the intent of Congress with the authorization of \$3 million for demonstration programs in home health care.

With the rapidly increasing cost of care in hospitals and extended care facilities, it is vital to our economy that we find other ways of caring for those who need assistance, but who do not need to be in an institution. In most instances, it has been found that care at home is less costly than in an institution, and it is certainly more humane. Furthermore, patients recover more quickly from an illness requiring hospitalization if they can be returned to their home setting as soon as possible.

In-home services are one means of preventing institutionalization. Another way would be to provide financial and service support to families, which may be of sufficient help to enable them to provide a home for an older person. Data from a Cleveland survey suggest that 81 percent of families will accept older people in their home with certain incentives. Approximately 19 percent would not take in older persons under any condition, and most of these felt that the Government should be responsible. It is my belief that the responsibility should be shared by the families, the community, the individuals, and certainly to some extent the Government.

We have a situation today in which families need to be strengthened and enriched, which can be done by including older adults in their households. This I tried to provide by my amendment No. 188 to H.R. 3477, which recently passed the Senate. Unfortunately, it was lost in the House-Senate conference. However, I will continue my efforts in this regard through S. 1014, which I have introduced in the Senate and which would provide a tax incentive for those who keep elderly dependents in their homes.

Congregate housing and day care centers also are alternatives. I trust that these hearings will not only help us to make better and more efficient use of the resources we now have, but also perhaps will show us additional ways by which we can avoid unnecessary institutionalization, thereby offering more options of choice in living arrangements to our senior citizens.

Senator CHILES. Thank you, Senator Domenici.

Because of the extensive interest by the House Select Committee on Aging in these particular issues, we invited Chairman Claude Pepper and other members of the committee, and we are delighted that Con-

gressman William Cohen has been able to be here today and that Congressman Pepper will join us tomorrow.

Congressman Cohen, we would be glad to have any statement that you might have.

**STATEMENT BY HON. WILLIAM COHEN, A REPRESENTATIVE IN
CONGRESS FROM THE STATE OF MAINE**

Representative COHEN. Thank you very much, Mr. Chairman.

I should point out, Senator, that while Mr. Pepper will be here tomorrow, he could not be here today and asked me to fill in for him.

I welcome the opportunity to join my distinguished colleagues on the Senate Special Committee on Aging. I appreciate the time and attention your committee is giving to the policy problems and fragmentation of Federal home health services. I point out that our committee has been involved in this issue since January 1976.

I recall we had a similar meeting about a year and a half ago on the same subject, and yet I have not perceived that much has changed in the way of a Federal commitment to home health care. Although few would now dispute the necessity or the desirability of home health care, Congress and the administration have been reluctant to make this service available without assurance that the public dollars needed to support such care would be well spent.

In the meantime, we have been plagued with soaring health care costs. Our national health expenditures have risen over the last half century and the recent rate of increase, reaching into double digits, is unprecedented. Home health care costs, as you pointed out, Mr. Chairman, have also risen during this period, but these expenditures have fallen off as a percent of the total medicare and medicaid dollars which reflects our bias to other modes of health care.

"SEARCH FOR ALTERNATIVES"

The significance of the cost crisis in health care took on a new dimension with President Carter's proposal to limit inpatient hospital costs. The ramifications of this step have yet to be fully explored. However, it has focused our attention once again on the search for alternatives of innovative options to traditional kinds of patient care.

I think it is premature to argue that home health care will result in significant cost savings if the necessary liberalizations to eligibility groups and covered services were made to present programs. Nevertheless, I think we on the House side agree it is much more humane and compassionate, and certainly indicative of our free system of government, to give the elderly, sick, and disabled a choice to stay in their own homes. I think as we recognize our reliance on institutional care for acute illness, we should not be prevented from encouraging other health maintenance mechanisms which will postpone costly inpatient care. So in this sense I think home health care and other in-home services should be regarded as a preventive resource in our quest for health.

I just make one other point, Mr. Chairman, and I think you touched upon it briefly. In order to assure access to home health care, it is going to be necessary to provide appropriate incentives to encourage its growth and development, but greater stimulation of the home health

industry is not necessarily going to provide better care if we fail to provide standards to identify agencies with programs that warrant public and professional confidence. Many of my own interests in this field of home health care have centered on the necessity of standards. As a forerunner to sorely needed legislation which will expand home health services, I think the standards are an essential step in the evolution of a more uniform coordinated and rational approach to the Federal financing of home health care.

As a matter of fact, I recently introduced H.R. 6299, which would set up standards for the home health care industry. It seems to me we have to do this so we avoid what is now taking place with respect to the fraud and abuse in our medicare and medicaid systems that we now seek to correct by imposing impunitive measures on those who abuse these programs. So as we move to broaden America's continuum of health services through home health care, I hope we can come to a clearer understanding of what assurances we need to protect against program abuses and to promote the quality of care by our deliberations today.

I thank you again for inviting the Members of the House to join you. May I say that one of the other reasons I am here is that a constituent of mine is on the witness stand today, Robert Liversidge, from Bath. "Chip" has been a very important witness to the committee in the House. I welcome you here today, Chip.

Senator CHILES. Well, it seems that all of us on the panel have a witness here today, so the Chair is going to exercise its privilege and call on the Florida witness first.

Before we hear from the witnesses, I would like to insert into the record a statement submitted by Senator Spark Matsunaga.

[The statement referred to follows:]

STATEMENT BY SENATOR SPARK MATSUNAGA

Mr. Chairman, I commend you and the members of this committee for your diligent efforts to explore alternatives to costly institutional health care for the elderly and medically indigent.

One of the most challenging and demanding problems we face in attempting to lower the cost of health care is to find ways to promote the use of noninstitutional delivery patterns which will provide high quality health services to the general public at a lower cost.

I firmly believe that an important and fundamental component in the establishment of alternative patterns to institutionalized health care delivery is the greatly increased utilization of existing pools of qualified and highly skilled health professionals in the country such as registered nurses, nurse practitioners, nurse clinicians, and licensed practical nurses for outpatient and home health care.

Currently, registered nurses in all States and nurse practitioners and nurse clinicians practicing in States which have amended their nurse practice statutes to include these relatively new professional nursing groups are providing independent health care in outpatient clinics and in the homes of many American citizens. In addition, licensed practical nurses are trained and authorized to provide basic nursing services in all States and in most States they are currently providing such services in a wide variety of settings, including the home under the supervision of a physician or registered nurse.

Mr. Chairman, it is widely known that for many years nurses have filled an indispensable role in the provision of much needed health care services throughout the country, especially in the remote rural and inner city areas where severe shortages of all health and medical services have historically existed and continue to exist to a very significant extent today. However, to date, no Federal legislation has been enacted to encourage the direct provision of outpatient

and home health care by these highly skilled health professionals even to our Nation's elderly and medically indigent, the two segments of our population which are widely recognized as having the greatest demonstrated need for increased outpatient and home health care.

ARCHAIC RESTRICTION MUST BE REPEALED

Under the current provisions of the Social Security Act, health care services must be provided by or under the direct supervision of a physician. This archaic restriction on the practice of fully qualified professional nurses who, in fact, have provided independent, unsupervised health care to the general population for many years and are continuing to provide such services, must be repealed if cost-effective patterns of high-quality, low-cost noninstitutionalized health care delivery are to be established.

In the previous two Congresses and in the present Congress I have supported legislation which would provide for the inclusion of all registered nursing services for direct reimbursement under the medicare and medicaid programs. I have also supported similar legislation in the previous Congress for licensed practical nurses.

If enacted, these proposals would create a significant financial incentive for these health professional groups to make a direct contribution toward the establishment of a viable alternative to current patterns of institutionalized health care delivery for the elderly and medically indigent.

Mr. Chairman, at present there are many excellent examples which have demonstrated that the increased provision of outpatient and home health care will cut the total annual expenditures in the health care industry by cutting down on the length a patient stays in health care facilities. It has also been shown that the provision of outpatient and home health services will significantly improve the health and well-being of certain types of major surgery patients and chronic illness patients by shortening the length of stay in the health care facility and returning the patient to the familiar, more comfortable, and restful surroundings of home at an earlier date.

I believe that the enactment of legislation to permit registered nurses, nurse practitioners, nurse clinicians, and licensed practical nurses to provide outpatient and home health care beyond the present provisions of the Social Security Act would prove of great assistance in the establishment of effective and efficient alternatives to the present patterns of institutionalized health care delivery for the elderly and medically indigent.

The enactment of these proposals would also establish more firmly important patterns of high-quality, low-cost health care delivery in preparation for the enactment of a national system of comprehensive health care delivery. I therefore wholeheartedly urge your favorable and strong support of legislation which would increase the participation of nurses in the provision of health care to our Nation's citizenry.

Senator CHILES. Now we will hear from Mrs. Dolores Wennlund, public health nursing program supervisor of the Florida State Department of Health and Rehabilitation Services. Mrs. Wennlund has been a witness before and has provided valuable testimony. We are delighted to have you before us today, and would be pleased if you would give us your statement.

STATEMENT OF DOLORES M. WENNLUND, R.N., M.S., PUBLIC HEALTH NURSING PROGRAM SUPERVISOR, DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES, STATE OF FLORIDA

Mrs. WENNLUND. Senator Church, Senator Chiles, and the other members of this committee are to be commended for your concerns about the health needs of citizens, particularly senior citizens. I share these concerns and am grateful for the opportunity to address the committee.

My responsibilities in Florida State government are to identify the

needs for community nursing services, plan and evaluate nursing programs, establish standards, and to stimulate improvement and expansion of services. The thrust of our department is toward the promotion, maintenance, and restoration of health. Major goals include the reduction of dependence and institutionalization. Services are multidimensional, including health and social components. They are different from the medical model found in acute care settings.

There are 2 million people in Florida who are 60 years of age or older, almost one-quarter of the population. This group constitutes a major reservoir of need for health services, particularly long-term care.

State efforts to address the needs of the aged and chronically ill include the Nursing Home Ombudsman Act, establishing State and local committees to watch over the rights of nursing home residents; the Adult Congregate Living Act requires licensing of home health services and adult congregate living facilities; the Omnibus Nursing Home Reform Act requires establishment of continuing education programs for nursing home personnel, classifying nursing homes according to quality of care and compliance with rules, and scaling Medicaid reimbursement by classification.

LONG-TERM CARE TRAINING

Florida is fortunate to be a participant in a project with the Association of State and Territorial Directors of Nursing, sponsored by the division of long-term care. The product of the project is a modular curriculum designed to train long-term care nursing personnel in rehabilitation nursing. The 1977 State legislature is considering a bill to establish outpatient geriatric nurse clinics in nursing homes. Evaluation of these efforts will not be complete until they are fully operational, which is contingent on adequate funding.

Efforts to provide alternatives to institutionalization have not been widely successful. Bias toward acute care permeates the health care system. This bias has sired regulatory controls that limit eligibility and funding for Medicare benefits. Many chronically ill persons require more than medical care. Nursing care is a predominant need and often over relatively long periods of time.

Nursing is a professional health service that makes a distinct and unique contribution. However, Federal regulations selected a series of medically oriented tasks and observations, defined them as "skilled" nursing care, and limited reimbursement eligibility to these tasks, thereby eliminating many preventive and maintenance services needed by the chronically ill. Judgments made by fiscal intermediaries fail to take into account extenuating circumstances that modify the level of care. For example, one patient who had eye surgery needed one drop of rather potent medication instilled in each eye for an extensive period. The patient and her husband were both elderly, frail, and palsied. Neither one had the visual acuity nor hand control needed to accomplish the treatment. Despite careful and repeated justifications, payments for visits were denied. Fortunately, the public agency continued this service.

When services can be provided on an intermittent basis, a respon-

sible caretaker is available and the setting is safe, then home health services are a reasonable alternative to institutionalization. However, there are problems that must be resolved first.

"GRANDFATHER CLAUSES"

Private home health agencies have enjoyed prolific growth in Florida despite licensure regulations and requirements for statements of need. Strong lobbying for grandfather clauses and exemptions and the lack of tested criteria to determine need and Federal legislation detract from a strong stand on this issue.

There are presently 183 applications for licensure filed with the office of licensure and certification. Of these, there are only 12 health departments, 4 combined agencies, and 5 visiting nurse associations. In 1970 there were nine public or voluntary agencies for each private one. Today, that ratio is reversed. There are nine private agencies for each public or voluntary one.

A health service agency in south Florida, reporting a sharp rise in the number of private agencies, notes that they make twice the number of visits at twice the fee for visit, thereby costing four times that of the local visiting nurse association. The average cost per case in 1976 was \$226.75—double the 1973 cost of \$108, and quadruple the 1971 figure of \$47.

The sharp rise in the number of private agencies which accept medicare only, coupled with the rigid interpretation of "skilled care," are causing grave hardships among visiting nurse associations and county health departments which provide long-term maintenance care and were the pioneers in this service from the turn of the century. Analysis of 1976 data reveals a steady decrease in the percent of the caseload eligible for medicare reimbursement and a rise in the percent of free visits.

In one county, total visits have increased only 10 percent, but free visits have doubled. A comparison of the first and last quarter of 1976 shows:

Source of payment	Percent of caseload	
	January-March 1976	October-December 1976
Medicare.....	59	51.0
Medicaid.....	3	3.5
Full fee.....	1	1.0
Other.....	3	.5
Part fee*.....	13	17.0
Free.....	21	27.0

*This would include veterans and 3d-party payees.

* Often about 25 cents; it is a very small part.

Medicaid pays a fixed fee: \$13.50 per home visit by an R.N. and \$7.50 for a home health aide visit. This is less than the cost of the service. Therefore, almost half the caseload must be subsidized through another source. Such subsidies are hard to come by and sometimes impossible. Orange County Visiting Nurse Association had a \$60,000 deficit in 1976, when 8,100 visits were made. The medicaid fee is only half the cost of a home visit. Medicare reimbursements do not fully

cover the costs of orienting new nurses, visits to supervise home health aides, or expenses for ineffective visits; that is, when the patient was rehospitalized, expired, or was not at home and failed to notify the nurse. The Director states that unless funds are found in the community, services to the medically indigent will be curtailed. Strenuous efforts in this pursuit are partially successful. Patients with some type of reimbursement, even though inadequate, are being seen. Free visits are being discontinued as of this month.

The Jacksonville Visiting Nurse Association reports they are now seeking a \$35,000 subsidy from the community as they experience the same kinds of difficulties. Two county health departments are expressing concern that they will not be able to subsidize home health services much longer. There are presently only 16 county health departments or combined agencies certified to provide home health services—a 61-percent decrease from the 41 certified in 1970.

The total medicaid budget in Florida has increased 20 percent in the past year to \$227 million. Medicaid pays for 15,000 nursing home residents, or half the total caseload. This consumes more than 36 percent of the total budget. Less than 1 percent pays for home health services. It becomes increasingly evident that there must be some changes to achieve the goals of the department of health and rehabilitative services in Florida; that is, to reduce institutionalization and dependence.

Other avenues must be explored to find safe and reasonable alternatives to institutionalization. Freer access to nursing care should be explored. In one county with a caseload of 60 admissions in a month, 5 patients were discharged because they lacked medical care. Public health nurses can and do assess the nursing needs of patients. They often develop the treatment plan and send it to the doctor for signature. Without that signature, patients are denied health care and even that care which nurses are licensed to give. There are always a few patients who refuse medical care for whatever personal reason. Nurses carry a heavy burden of guilt when they are unable to convince the patient to see a doctor and then must deny the patient care themselves. Broader use of nursing specialists in initiating and continuing care should be considered.

Reimbursement for long-term care, including rehabilitation and maintenance at home under the supervision of public health nurses or nurse practitioners, is needed if we really hope to reduce the nursing home population.

STEPS FOR IMPROVEMENT

Quality control and avoidance of misutilization can be achieved through the following mechanism:

First, multidisciplinary professional review teams should review records and follow up complaints or questions.

Second, professional standards for practice based on the American Nurses Association standards should be developed for specific types of care. We have begun this work and have completed public health nursing standards of care for chronic obstructive pulmonary disease.

Third, the most effective control measures are informed consumers who know what to expect in services and are aware of their responsibility in self-care. I invite my colleagues in the Association of State

and Territorial Directors of Nursing to develop consumer information so that the patient and family can judge the quality and extent of care they are receiving and direct questions and complaints to the appropriate authorities.

Lastly, as with other public funded services, all home health agencies should be required to provide a designated percentage of their services to indigent patients if they are to receive public funds.

Thank you.

Senator CHILES. Thank you very much for your comprehensive statement, Mrs. Wennlund.

I find it startling that the private agencies are making double the visits at double the fee. It is easy to understand why the public agencies are finding themselves put to the wall, their having to pick up, I guess, all of the free cases.

Mrs. WENNLUND. That is right.

Senator CHILES. And all of the money is being siphoned off. What kind of control can we put on this?

Mrs. WENNLUND. Only through standards and demanding that patients really be rehabilitated, instead of care being given to them and no question of teaching the family and no evidence of trying to stimulate personal responsibility for health.

Senator CHILES. Then in many instances—not in all, but in many instances—you would say that the term “for-profit agencies” is a very good term. It is really for profit?

Mrs. WENNLUND. Oh, it is.

Senator CHILES. And not for rehabilitation or for service?

Mrs. WENNLUND. Exactly.

“REVERSING THE TREND”

Senator CHILES. Well, I think, as we have said earlier, there is nothing wrong with the for-profit motive, but it certainly indicates that some responsibility and accountability has to be built in, or we are going to see this happen. Do you see any way of reversing the trend we now see of the public agencies and visiting nursing associations—which have been in existence over a long, long period of years doing, in many instances, a very good job with limited resources—going out of business?

Mrs. WENNLUND. I suspect by following some of these recommendations in terms of setting standards and seeing that they are through the PSRO activities and really reviewing what is happening to patients in the home care—the same as they do in nursing homes and in hospitals.

Senator CHILES. Also, we would have to do something better about funding those public agencies, would we not, through changing some of the crazy ways the funding is set up under medicaid and medicare?

Mrs. WENNLUND. Yes; and I suspect that is looking at long-term care as something that is not the end of the road and that acute care is the alternative, not preventive and maintenance care.

Senator CHILES. In the bill that you are talking about, why did the legislature pick nursing homes to do the geriatric outpatient nursing?

Mrs. WENNLUND. I would have to second guess the legislature, so I am not sure.

Senator CHILES. I mean as opposed to hospitals or the other places.

Mrs. WENNLUND. I believe that the nursing home industry itself sought this legislation, and they hoped to make greater use of treatment facilities that exist in the nursing homes that are largely unused.

Senator CHILES. Thank you. I will have some more questions to ask you, but I think we will go on with our panel now.

Dr. Friess will be our next witness, a physician in New York City, sometimes referred to as the angel who makes house calls.

STATEMENT OF CONSTANCE FRIESS, M.D., NEW YORK, N.Y.

Dr. FRIESS. A terrible title. Mr. Chairman, members of the committee, I am honored to have this opportunity to speak with you today.

There are times when we physicians, who care for the elderly in their homes, feel as isolated from the mainstream of medical care as our patients feel isolated from the mainstream of community life.

First, I would like to acquaint you with the nature of my work. I visit in the Yorkville district of Manhattan, which is the catchment area of my hospital, New York Hospital. About 70 percent of my patients live in dilapidated, walkup housing, which is sandwiched between high-rise elevator apartments where the other 30 percent live. Depression and loneliness cast their shadow over both groups and aggravate the common ailments of the elderly; namely, visual, hearing and memory defects, arthritis, cardiovascular and pulmonary problems leading to heart attacks, strokes, emphysema, diabetes, and nutritional disorders. Nutrition may be malnutrition or obesity. Unfortunately, except for the recent campaign to combat hypertension when it first appears, we have had little success in reducing the incidence of these disorders in later life.

In addition to these maladies, the elderly in America must combat a century of adverse cultural attitudes which displace the aged from the family unit either by institutionalizing them or abandoning them completely. I am very encouraged, though, to think that this is changing. Feedback from a recent Daily News article gives evidence that the young are becoming interested in the elderly. I personally feel that they have much to offer one another.

HOME CARE PROGRAM

I am going to confine my major remarks to two main points: First, since I am committed to the supposition that, given the proper supportive services, the elderly can be better cared for—and at lower cost—in their homes, I shall point out the difficulties I encounter in the present system and some possible solutions; and second, I shall speak briefly on the patient's failure to take responsibility for his own health.

Let me now discuss the needs, as I see them, in the home care program. First, homemakers are sorely needed. They should be part of the home health package, probably under certified home health agencies. There are no provisions for these under medicare and often there are 4- to 5-month delays under medicaid.

Second, nurses—both practical and registered—are needed to monitor medications, diet, rehabilitation following fractures, and so forth.

Medicare and Blue Cross will not pay for any of this, although it would prevent frequent hospitalizations.

Third, although not my field, there is a real need for legal and financial advisors who would visit the patient, when necessary, in his home.

The last problem is the cost of medications. Medicare does not cover these and pharmacies are beginning to refuse to fill medicaid prescriptions, due to faulty reimbursement. Over and over again I have patients taking half the medication prescribed because they want to stretch it out or they are not taking the medication at all because they don't have the money to buy it.

I believe that these problems would best be solved by having the health systems agencies create a separate section for home health. Membership should be drawn from intelligent, knowledgeable, and empathetic persons, both paid and, in some instances, voluntary.

All of this, of course, takes money, but in the long run, I believe it would be more economical than institutionalization. We must try different plans and discard those which do not work. For example, New York State, as of March 1, introduced a point system for admission to a nursing home.

Senator DOMENICI. Might I ask you a question?

Dr. FRIESS. Certainly.

Senator DOMENICI. On page 3 of your statement, the two sentences you read:

All of this, of course, takes money; but in the long run I believe it would be more economical than institutionalization. We must try different plans and discard those which do not work.

Let me just share a problem that I think we all have. We make that statement about developing a good program that seems to offer an alternative to institutionalization, but the authorizing committees in the Senate have a difficult time putting it into substance.

I have no doubt that a major home-health-care delivery system would save institutional dollars. Obviously, we could do some things that we are not now doing and maybe those services ought to be funded with new dollars. Do you have any ideas, based on your experience, or anything graphic to suggest to us that we can use in this particular area?

COSTS UP: FROM \$18 TO \$210 A DAY

Dr. FRIESS. Well, the only thing that I can say is that the cost for the semiprivate bed in a New York hospital since 1932, when I first started there as an intern, was in the nature of \$18 a day, and it is now up to \$210 a day. Now I don't know what the corresponding cost for employment of a home health aide, for example, in 1932 would have been; I am afraid I cannot answer that, but I doubt if the percentage increase would be comparable because I don't think wages have gone up that much.

Senator DOMENICI. On the other hand, the link that is missing is that one might say that there would be less of those \$210-a-day visits per annum if we had a better home health care system. We would not just claim for the inflationary aspects of each of the single deliveries.

Dr. FRIESS. No; it would be the time element as well.

Senator DOMENICI. Has anyone done any work on this, to your knowledge?

Dr. FRIESS. I am afraid we do not have the figures on it. I think this is one of the big lacks. I hope somebody on the panel can come up with something.

Representative COHEN. Would the gentleman yield?

Senator DOMENICI. Yes.

Representative COHEN. I believe the GAO has done a study with reference to home health care and found it more expensive. However, I have raised the question in my opening statement that if we were to liberalize the process and make more groups eligible, I question, in the long run, whether it is cheaper; but the real issue is, is it more humane and more compassionate and more consistent with our goals of trying to have older people maintain their integrity in their home? There is a study out by the GAO and I can obtain a copy of that for you.

Senator DOMENICI. Thank you.

I don't want my questions to be misunderstood, but it is just that there ought to be some evidence that we are really going to get more service per dollar by trying some of these programs. Everyone knows that institutionalization is a trigger, in many instances, for subsequent programs. It is the only way to take care of some individuals and that has to be having an impact on the average family using the institutional approach as contrasted with something else. I think that is just normal.

I had a doctor call me and tell me about a constituent saying, "I can't find a program that will fit so I am going to put the person in the hospital." When you push them, they are willing, not under oath, to say they don't need it but they don't have any other way, explaining, "Their kids can't be with them for a week or so; I am going to take care of a patient and medicare will pay for most of it."

Well, that has to permeate the system and it has to have an impact on the cost, as I see it. Unfortunately, I cannot put it into dollars so I cannot convince anyone yet. I think that we have to produce some type of model project so that we can study this concept in depth.

I thank the Congressman for his remarks.

Dr. FRIESS. New York State, as of March 1, introduced a point system for admission to a nursing home. The theory was sound—namely, to ascertain during the 3-day required stay in a general hospital what level of care the patient really needed. Skilled nursing or nonskilled, 180 or more points are necessary for a skilled nursing facility, and only a skilled nursing setup makes the patient eligible for some medicare benefits. I have given the committee some of the forms so you can see how complicated they are.

Application is then made to five nursing homes within a 50-mile radius of the patient's home and the patient is admitted to whichever one has the first vacancy. However, as the system is working, it results in long delays in the general hospital and encourages fudging on needs in order to be classified as needing skilled nursing care because it is only that part which is reimbursed. Often the patient's point system has to be revised by the time the bed in the nursing home is available. It is very clumsy and requires a lot of wasted effort.

It has been suggested that instead of nursing homes, foster homes for the elderly, where an intelligent, warm, empathetic couple or single individual could care for two or three persons would enable physicians to accomplish several visits under one roof, dilute the patient's loneliness, and relieve the patient of planning, shopping, and cooking meals. Of course the points leveled against nursing homes could also apply to the foster home because it boils down to the integrity, intelligence, and the training of the individuals who run them.

MAJOR PROBLEM: LONELINESS

I would like to give you a very brief illustration about an 82-year-old retired registered nurse who, 2 years ago when I first saw her, was living on the third floor of a rundown walkup. Her opening remark was, "My major problem is loneliness." It was said in a whisper and the pale eyes in the fragile body reflected fatigue, as well as sadness. Born in England in a Liverpool ghetto, orphaned at 4 years, R. S. had struggled most of her life to make meaningful friendships. In recent years these were terminated by death. After getting her R.N. in Saskatchewan, where she practiced for many years, she moved to Brooklyn, nursing until the age of 77. She then moved to Manhattan, thinking she would be less lonely.

When first seen, R. S. said, "You'd better go home, Doctor, because I have no money to pay you." Like many of the elderly, her income is just above that entitling her to medicaid, \$124 monthly from social security, and \$2,600 savings in the bank. The meager bank account is always inextricably bound to the last shred of independence. The thrust of the social service agencies today is to persuade the R. S.'s to spend that money in order to become eligible for medicaid, but the R. S.'s don't want to go on welfare.

As the interview progressed, many physical complaints evolved, but the physical exam revealed a paucity of abnormal findings. As I was speculating as to what R. S.'s chest X-ray and electrocardiogram might show, I was startled by her saying:

Doctor, I was taken in an ambulance to Lenox Hill Hospital the other day. They did all sorts of tests and after 3 hours they sent me home, saying there was nothing wrong with me.

I immediately called the hospital and was told:

I'm sorry, Doctor, since you are not on the staff you will have to get a signed permit from the patient asking for release of the information, and if you will send us that we will get it to you.

Well, I got it about 4 or 5 weeks later, but that was not very helpful at the moment.

Actually, at the end of several visits it turned out that her basic problem was nutritional. She no longer had the strength to navigate the stairs to shop. She ate little, if any, protein. If someone offered to get it for her, she lived mostly on baby food.

I finally said, "If I could arrange to get you into a nursing home, would you go?" This very soft spoken woman, who spoke barely in a whisper, emitted such a vehement "No" that I was somewhat startled.

Actually, as it worked out, 2 months later she was sent to a nursing home. Her savings account had been used up and she died about 6 months later.

In summary under my first point, my job would be easier and would free me to take on a larger caseload if home health personnel under categories of housekeeping, nursing, legal and financial aid were available to homebound patients and if medications could be financed through medicare as well as medicaid.

Turning to my second point, patient responsibility: We are all aware of the frustration which results from patient failure to follow through on sound advice. For example, C. W. is a 79-year-old retired butler who lives on the fourth floor of a walkup. When first seen 2 years ago, he was found lying disoriented in a dirty bed in an apartment smelling of urine. His screams, on being turned over, were due to large pressure ulcers on his buttocks. He was emaciated and dehydrated, had emphysema, and an enlarged bladder due to retention of urine from prostatic hypertrophy. He refused to go to the hospital, but would give no reason except that he did not wish to die.

With the help of the Visiting Nurse Association, this man's condition gradually improved. Intravenous fluids, a proper diet, and monitored medications did the trick. However, today—2 years later—C. W. is still smoking three packages of cigarettes daily and has steadfastly refused to have a prostatectomy to relieve his urinary obstruction. From this short vignette one sees that even with excellent home care the outcome may leave much to be desired because the elderly, for a variety of complicated reasons, do not follow through on the recommendations.

RECOMMENDATIONS

In conclusion, I have tried to point out what the problems are and now I would like to suggest possible remedies:

(1) Efforts should be made to utilize community talent and energy in providing supervised, trained, intelligent extra hands and heart in the home. This should be under a separate division of home care in the health systems agency.

(2) Enlist more doctors in home visits by decreasing paperwork and increasing reimbursement.

(3) Consider altering our criteria for selection of medical students and paramedical personnel. These should be chosen for their integrity, empathy, and awareness of human needs, as well as their brilliance and native intelligence.

(4) Establish a central clearinghouse for hospital records in order to reduce reduplication and fragmentation of medical care, thus saving society considerable money.

Many of the patients had five different general hospitals—they will go to one for their heart, another one if they have a fracture, another one for skin diseases, and so forth.

Lastly, and this is somewhat facetious, how about having Congress and President Carter declare a "grandmother's and grandfather's day" in order to focus public attention on the elderly?

Thank you.

Senator CHILES. Thank you very much, Doctor.

Our next witness will be Susan Kinoy, associate executive director for program services, Community Council of Greater New York, New York City.

STATEMENT OF SUSAN K. KINOY, ASSOCIATE EXECUTIVE DIRECTOR FOR PROGRAM SERVICES, COMMUNITY COUNCIL OF GREATER NEW YORK, NEW YORK CITY

Ms. KINOY. Thank you very much, Senator.

I think the definition given by our last witness of a person who works in the home, "a person with another pair of hands connected to the heart," is most appropriate.

Senator CHILES. We were talking about that up here, too.

Ms. KINOY. I speak today for the council's citizens' committee on aging. The community council brings together service providers from the voluntary and public sectors, as well as representatives of citizen groups, unions, and other civil organizations in New York City. Its major functions are information, research, monitoring, and convening of individuals and organizations around key social issues in New York City and helping them, when appropriate, to take action on those issues. We welcome the opportunity to testify today before the Senate Special Committee on Aging.

It gives me special pleasure to be here today because we first made recommendations to your committee concerning care in the home in 1969. It was based on an analysis of the fairly new legislation and the then-operational programs. This year, as in 1969, we are provided with Older Americans Act title III funds, through the New York City Department for the Aging, to conduct a systems analysis of New York's home attendant program.

There are many systems of home care, including provision of home health aides, homemakers, housekeepers, and home attendants. Presently, these personnel function under a variety of laws, funding programs, and administrative structures. The primary funding sources for these programs are titles XVIII, XIX and XX of the Social Security Act. Many of these programs are working well.

Today, I am only going to discuss the New York City home attendant program, the only program in New York City where clients or their families select the home care worker. New York City several years ago, in an extremely creative and generous manner and using title XIX and title XX funds of the Social Security Act, created a unique, much-needed, and very large home care service for chronically ill and aging persons: the home attendant program. The last 4 years has shown an increase in usage from 2,000 to 14,000 chronically ill persons with 200 cases per month being added to the rolls.

"UNIQUE AND NEEDED SERVICE"

We commend New York City for the development of this unique and needed service. It was brought into being precisely because medicare—title XVIII—is a health insurance program which only can provide a home health aide for short periods of time under the direct supervision of a nurse or other professional and only during such times as a person has a medical condition that is unstable or acute. The home health aide may only provide personal care; she does not perform housekeeping or chore services. In addition, title XVIII does

not provide long-term, in-home, supportive, or maintenance care for plateaued or chronically ill persons.

Title XX, on the other hand, can provide housekeeping or chore services for longer periods of time to persons who qualify below certain income levels. No requirements exist for medical supervision. In addition, there is a ceiling imposed on title XX funds.

Title XIX—medicaid—must provide health supervision to home care workers who administer personal care.

Therefore, the home attendant service uses a combination of titles XIX and XX administrative procedures.

The home attendant service differs from homemaker and housekeeping service in that the home attendant usually provides both personal care and chore service for over 20 hours per week.

Home attendant services are given primarily to persons who are bedridden or wheelchair-bound or who cannot be left alone for significant periods of time. The services provided include such chores as shopping, preparing meals, housecleaning, bathing, toilet activities, ADL, et cetera.

Home attendants, at the present time, need not have initial health-related training, and they are either chosen by the client—no immediate family member may be employed—or assigned by the family and adult service division of the department of social services (DSS) roster unit, which maintains a file of active home attendants. Home attendants are under the employ of the client, who pays them at the rate of \$2.75 per hour by means of a two-party check that is issued on a biweekly basis. The salaries are paid from medicaid funds—title XIX of the Social Security Act—with the Federal Government contributing 50 percent, the State 25 percent, and the city 25 percent.¹

The general profile of persons receiving home attendant service is the following: Median age, 77; 70 percent of referrals are from hospitals; average cost per person, \$11,000 to \$12,000 per year.

The program is coadministered by several divisions of the human resources administration in New York City and implemented by three different systems according to borough.

Needless to say, within this very large program there has been fragmentation, immersion in bureaucratic detail with poor communication among the many agencies, resulting in long delays in service delivery, poor selection and supervision of the home attendant, lack of guidelines at both city and State level, and uncontrolled growth.

I will not spend my few minutes of testimony presenting a litany of "horror stories" about this program. Rather, I will describe some of the problems and make recommendations for their improvement.

I wish at this time to stress that the city and State are fully cognizant of many of the problems. The city department of social services is now actively involved through a task force, in which we participate, to restructure the program within the present laws. I think there is only so much that can be done within the confusion of the many laws under which this program must operate.

GETTING INTO THE SYSTEM

The first problem is getting into the system. Home attendant service is available only to persons who are certified as medicaid eligible. Those patients in hospitals, the majority of home attendant users who

¹ Human Resources Administration, Project Plan: Home Attendant Program-Improvement Project, April 1977, p. 1.

require complex processing to obtain their medicaid eligibility, must negotiate this system on their own. In the main, if they are unable to obtain a friend, relative, or a voluntary agency to assist them and are incapacitated, they are out of luck. Sometimes, local department of social service service workers assist in the medical application.

Hospitals, with the financial and medical pressure for discharge planning, often will not refer patients for in-home services unless they are certified for medicaid because of the 6- to 8-week waiting time for medicaid approval. It is easier for hospitals to institutionalize these patients.

DSS service workers will not initiate home care applications from hospitals until the patient is home. Generally, the first visit is made within 2 weeks. By this time, many of the patients have to be readmitted to the hospital because they are unable to manage on their own. Some deteriorate to the point that they now require nursing homes.

Home attendants receive \$2.75 per hour with no benefits, no social security, no vacation time, and so forth. They usually are not given travel expenses.

The home attendant is generally an unskilled worker, including some illiterates. Some home attendants do not speak English and are unable to read the instructions on medicine bottles.

The screening and selection of home attendants by patients or families is often poor. No criteria has been established for these functions. In addition, families are so desperate to get someone to stay with the patient that they frequently settle for anyone who will do the job. This has led to cases of physical or emotional abuse of patients by workers—I am sure you have read some of the headlines in the papers recently—stealing from clients, and so forth. On the other hand, a frequent concomitant of chronic illness and aging is impatience, forgetfulness, anger over details, and exaggeration of problems.

There is often dismissal of worker by clients for questionable reasons. We were reminded about the old alcoholic hiring another old alcoholic attendant, and in this case there are many problems. Often patients refuse home attendants from differing cultures, nationalities, or ethnic groups. However, when a recipient has recruited his or her own home attendant, it has sometimes been more satisfactory, especially when language and cultural backgrounds are similar.

Training and orientation of the home attendant conducted by DSS has been sparse. Often there is no training at all.

Payment of home attendants has been the most glaring problem in the program. Because of staffing shortages and the city's freeze on hiring, thus limiting payroll personnel, home attendants have had considerable delays in payment and often worked without pay for a number of months. Many have been forced to leave because of lack of pay. All payments are made by two-party checks and this leads to vast administrative nightmares. A check made out to a worker who has left or has been fired must be returned and a new one issued to the second or third worker on the job. Families cannot advance money because checks are made out to specific home attendants.

Supervision of the home attendant is the responsibility of the Visiting Nurse Service because it is medically oriented and paid for under medicaid. It usually involves an initial visit after service is initiated, and thereafter a 6-month assessment visit, unless otherwise indicated.

For the most part, the supervision is inadequate since the home attendant reports only to the ailing recipient. Recipients have been reluctant to complain about lack of coverage, and they are often hesitant to report abuse by the home attendant for fear that service would be removed.

Local department of social services offices are assigned case management in the present system. This really involves reauthorization for this service every 6 months. This is the sum total of the service supervision of the home attendant and recipient.

SUGGESTIONS FOR ACTION

We make the following recommendations:

(1) Congress must be made aware that home care of all types must be utilized as a viable and ongoing alternative to institutionalization. This is especially true for long-term chronically ill or feeble older persons.

(2) Federal legislation must be passed which will guarantee that there be a unified administrative and payment structure which will "marry" or combine health care and social supports for the chronically ill patient or the person whose medical condition has plateaued. This would eliminate a local community's need to create a complex structure using three existing legislative programs—titles XVIII, XIX, and XX.

(3) Federal legislative guidelines must provide that all prospective workers be screened by the supervising agency in relation to health, mental health, education, reading ability, language, reliability, work record, attitudes toward illness, and so forth. If a patient or a family member selects a home care worker, this worker must be selected from a roster of persons who have been screened by an agency according to specific criteria and trained by an agency using carefully evaluated criteria. A temporary arrangement with another worker should be made in order to keep a client at home when a person selected by the client is being trained.

(4) We wish Congress to be aware that delays entering the home care system result in longer, expensive hospital stays. Therefore, pre-discharge planning must be conducted to guarantee smooth intake into the home care program. Medicaid eligibility for home care, wherever possible, should be determined while the person is hospitalized.

(5) It is a Federal responsibility that home care workers be paid adequately in relation to Federal and local minimum wage standards. They must at least be protected by such benefits as workman's compensation and social security, and preferably be covered by sick leave, vacations, and unemployment insurance. Transportation funds must also be provided.

(6) Supervision of workers must be both adequate and timely.

In conclusion, in order to effect these recommendations, we advocate the vendorization, either by a public or voluntary agency, of all aspects of a home care service for long-term chronically ill persons. This would include responsibility for training the worker, the matching of a client with a trained worker, helping the client to find a worker if a suitable person is not available, the supervision of the worker, and the ongoing observation, in cooperation with all disciplines, of the social and health needs of the client.

In this way, through an effectively coordinated service, a high quality of care can be guaranteed and regular and timely payments can be made.

Thank you very much for giving us an opportunity to appear before you.

Senator CHILES. Thank you.

Our next witness will be Judith Walden, a registered nurse, and director of Hospital Home Health Care, Albuquerque, N. Mex.

STATEMENT OF JUDITH WALDEN, R.N., DIRECTOR, HOSPITAL HOME HEALTH CARE, ALBUQUERQUE, N. MEX.

Mrs. WALDEN. Thank you, Senator.

I am Judy Walden, a registered nurse; the original and current director of Hospital Home Health Care in Albuquerque, N. Mex. Our home health agency is a joint venture between two hospitals in Albuquerque: St. Joseph Hospital and Presbyterian Hospital Center.

Home health care services that are provided through a qualified, coordinated program can do a great deal to meet the health care needs of our country. Home health care is an integral part of the total continuum of our health delivery system. Through a reasonable funding mechanism and increased community and professional awareness, this resource can provide a viable alternative to inappropriate institutionalization.

There are many definitions of home health care, but I prefer the broad definition that has been approved by the American Hospital Association board of trustees and endorsed by the board of directors of the National Association of Home Health Agencies, the National Council of Homemaker/Home Health Aides, and the National League for Nursing. That definition is:

Home health services is that component of comprehensive health care whereby services are provided to individuals and families in their place of residence, for the purpose of promoting, maintaining, or restoring health, or of minimizing the effects of illness and disability. Services appropriate to the needs of the individual patient and family are planned, coordinated and made available by an agency/institution or unit of an agency/institution organized for the delivery of health care through the use of employed staff, contractual arrangements, or a combination of administrative patterns.

These services are provided under a plan of care that includes, but is not limited to, appropriate service components such as medical care, dental care, nursing, physical therapy, speech therapy, occupational therapy, social work, nutrition, homemaker home health aide, transportation, laboratory services, and medical equipment and supplies.

Concern over the total delivery of health care services is especially important today with the current national focus on economics. Legislators and health professionals, however, must examine not only whether health care facilities are being properly and efficiently used, but also the questions of whether the facilities are meeting the total health care needs of the patients served. In particular, there is a critical need to evaluate the health care needs and available resources for the increasing number of elderly and disabled citizens.

MEANINGFUL HEALTH SERVICE

The home environment plays a significant role in promoting health and facilitating the healing process. Home health care provides a

meaningful health service for ill persons, speeding recovery and rehabilitation of individuals who have acute or chronic health problems, or allowing a person with a terminal illness the choice of a peaceful death at home. Potentially, the need for home health services could extend to ill persons of all ages, including children; however, for the purposes of this hearing, my presentation will be limited to problems and needs of the elderly.

Public hearings sponsored by the Department of Health, Education, and Welfare were held across the United States between September 20 and October 1, 1976; 903 witnesses addressed a variety of issues related to home health care from medicare regulations and increased need for quality assurance to the inclusion of home health services in certificate of need legislation. The report of these hearings is well worth reviewing as many suggestions and recommendations have been summarized in the HEW publication:

The primary concern expressed by the witnesses was for an expanded, coordinated range of high quality home health services as part of an essential continuum of health, social, and support services.¹

An overwhelming majority of witnesses shared the view that eligibility for home health services should be determined by the patient's needs and should be individualized. The Health Insurance for the Aged Act, title XVIII of the Social Security Act, has made available to nearly every American 65 years of age and older a broad program of health insurance designed to assist the Nation's elderly to meet hospital, medical, and other health costs. This program was enacted in 1965 and has since then become available to persons who are permanently disabled, after 2 years, and under 65 years of age.

The program, commonly known as medicare, includes two related programs: hospital insurance—part A—and voluntary supplemental medical insurance—part B. Home health care in the form of 100 home visits is available under both parts A and B of medicare. In order for the provider of home health services to be paid through medicare, the agency must meet the regulations issued under the Social Security Act known as the "conditions of participation"; that is, the agency must be certified.

Incidentally, in New Mexico this year we passed a law that will mandate insurance companies to offer the benefit of home health agents through a licensed home health agency.

Other States have enacted licensure laws and regulations for home health agencies, often mandating higher standards than the HEW "conditions of participation." Still a third mandatory set of regulations must be met by hospital-based programs if the agency is a department of a hospital accredited by the Joint Commission on Accreditation of Hospitals. Acute portions of the accredited hospital receives deemed status with HEW, but the home health agency does not; therefore, it must also go through an annual HEW certification process in addition to the JCAH accreditation process, and in some cases another annual review for State licensure. In addition to mandatory regulatory groups, two national associations have developed standards: The National League for Nursing/American Public Health Association ac-

¹ "Home Health Care—Report on the Regional Public Hearings of the DHEW," DHEW Publication No. 76-135, p. 1.

creditation program for home health agencies and the National Council of Homemaker/Health Aides approval program. A third set of standards is currently being developed by the National Association of Home Health Agencies. All of these regulations are aimed at quality assurance which is very important and very necessary, but somehow these assorted standards and regulations must be coordinated and universally accepted in order to assure that every home health program has met and continues to meet a high level of quality in the delivery of services to patients in their homes.

VARYING COSTS FOR HOME HEALTH

Once certified though, medicare and medicaid—in New Mexico—will pay for home health services, if reasonable and medically necessary, on a cost or charge basis, whichever is less. However, home health providers should recover their full financial requirements which currently is not possible. The cost of home health service varies from community agency to community agency and to the hospital-based program. By virtue of the mandated medicare cost finding system, a hospital-based home care program, as with other revenue-producing departments in the hospital, share in the cost of the support departments.

The effect of this determination causes the home care program to perhaps carry a higher dollar cost per visit than free-standing programs. However, it should be noted that all home health agencies' clientele and services are not automatically equal in the intensity, coordination, or delivery of their services. Hospital-based home care represents a natural extension of the hospital services to its patient population as part of the hospital's concern for providing for total patient care.

Reimbursement from medicare for home health care is dependent on patient eligibility and whether the care rendered is "skilled," as defined in the Medicare Home Health Agency Manual, HIM-11. This set of regulations is subject to various interpretations across the country by the fiscal intermediary for the home health agency. However, in all cases determination of a covered level of care is made by a disinterested person based entirely on a retrospective review of the patient's medical records as submitted by the home health agency.

A system of prospective or concurrent review is available through the professional standards review organization—PSRO—program. In New Mexico, certain hospitals and long-term care facilities have been delegated by the PSRO as being able to make their own determinations on covered care. In New Mexico, the institutions use R.N. utilization review coordinators and medical audit committees whose decisions on the medical necessity and appropriateness of covered care are accepted by medicare and medicaid as binding for payment. It seems to follow, then, that it is worth exploring through a properly financed pilot program whether home health agencies should also be included in the PSRO review system and allowed to become delegated by the PSRO to be responsible for determinations of covered home health services.

This system could prove to be more efficient, support more timely decisions, provide for concurrent review with appropriate modifications in patient care plans as indicated, perhaps reducing the heavy

paper load, and improving cash flow. If prescribed standards are met by the agency and professional assessment of the level of care is approved by the PSRO, proper utilization of services would result and thus have an impact on the costs of health care services.

Another artificial barrier found in medicare reimbursement policies for home health services is the separation of primary and secondary services. In order for a patient to receive occupational therapy, medical social service, or home health aide visits, there must be a need for skilled nursing, physical or speech therapy. If the patient care plan is developed to meet the goals of promoting, maintaining, or restoring health or to minimize the effects of illness or disability, the total array of services needed to meet the goals should all be considered primary, and payment for one service should not be dependent on a requirement of another service. Neither should payment be based on such artificial requirements as a 3-day period hospitalization or a limit be placed on an allowable number of home visits.

Many stroke patients need an intensive program of physical, occupational, and speech therapy in addition to nursing and home health aide visits in order to fully realize their rehabilitation potential. It doesn't take long in these cases for a patient to exceed the 200 home visits under parts A and B of medicare. I am sure in some places this patient is put in the hospital for 3 days to become reeligible for more home visits. On the other hand, many patients only need a single service and the professionally assessed goals can be met with five or six home visits or, in some cases, a single home visit following hospitalization will suffice. Since medicare requires intermittent care as a prerequisite for payment, this single visit is not reimbursable.

BENEFITS VARY FROM STATE TO STATE

Medicaid, however, will pay for a single evaluation home visit. Through title XIX of the Social Security Act, certain home health services are mandated, such as nursing visits, home health aide services, and medical supplies and appliances. Other services such as physical, occupational, and speech therapy are at the option of the State. Medicaid is administered through the State; therefore, covered benefits vary from State to State, with as few as 25 visits per year allowed in Texas, or 50 visits per year in Arkansas, to States with no number limit on visits, but with a requirement of prior authorization such as in my home State of New Mexico. This requirement of prior authorization can result in delay in starting needed home health services.

In New Mexico, medicaid eligibility for home health service somewhat parallels medicare in the skilled and homebound requirements; however, there is no separation of secondary services. Fortunately, medicaid in New Mexico has chosen to allow the optional therapy services and will pay for any or all services, except medical social services, if deemed medically necessary by the PSRO and when prior authorization is obtained after the initial evaluation visit.

With both medicare and medicaid, payment for home health service should be based on a professional assessment of the patient's needs and service should follow a well-thought-out care plan. Payment should not be hindered by artificial categories of covered care. With the elimination of these recognized barriers and the provision for the

acceptance of equivalent standards, quality care can be assured by the home health agency as the patient mover through the continuum of health care services.

In 1972, the American Medical Association adopted as policy a report supporting the concept of home health care, and in that same year a general accounting report to Congress did likewise. This report to Congress stated that:

The cost of building, equipping, and maintaining a modern hospital has become so great that it is no longer economical to use an acute hospital for convalescent care, treatment of chronic illness, or custodial care. Each community and health facility is responsible for developing a comprehensive and balanced range of services and facilities accessible to all.

The hospital, the extended care facility, the skilled nursing home, the individual patient's home, and ambulatory outpatient facilities constitute important facilities in the continuum of patient care in a community. Appropriateness of medical care depends on using the right facility for the right patient at the right time.¹

Growth and development of home health care services should be based on careful community planning for the total spectrum of health services. The hospital should take the initiative in the development of home health care, either through the establishment of a home health service or through formal coordination of hospital services with community based agencies. All levels of home health care should be available to the patient dependent on his professionally assessed needs. The hospital is often the best resource for the intensive level of home health care that assures continuity of care to hospitalized patients who are able to have their health needs assessed, coordinated, delivered and thus met through a home health service.

Data collected from a survey of hospitals done by the American Hospital Association in 1975, and reported in the 1976 edition of "Hospital Statistics," published by AHA, reveals that 451 hospitals administer home care departments. This is 6.8 percent of 6,592 hospitals reporting in the United States. Bureau of Health Insurance figures vary somewhat in that they report 280 certified hospital-based home health agencies of a total 2,361 agencies that are certified for medicare. Other types of providers of home health care are visiting nurse associations, health departments, community agencies, proprietary and private not-for-profit agencies.

There are 37 short-term community hospitals in New Mexico according to the 1976 AHA's "Hospital Statistics." There are an additional 17 other Federal, psychiatric, or long-term care institutions with a total of 3,634 acute care beds and 2,850 long-term care beds in hospitals for our 1 million population. There are at least 18 agencies in New Mexico offering a variety of home health services. Thirteen of these are certified for participation in medicare and medicaid. Of the remaining five or so agencies, there are at least four private nursing services and the Veterans' Administration hospital has a small home care unit. Of these 37 hospitals, at least 17 have programs or formally relate to certified home care programs for the benefit of their patients.

Hospital Home Health Care is a nonprofit, hospital-based program shared by the two largest voluntary hospitals in New Mexico—St.

¹ Report to Congress—"Home Health Care Benefits Under Medicare and Medicaid," DHEW B-164031(3).

Joseph Hospital and Presbyterian Hospital Center. It is the only hospital-based certified HHA in New Mexico. Our geographic area served covers a population of around 450,000. Since its inception in May of 1973, a wide-range of home health service of a generally acute or rehabilitative nature had been rendered in the form of 70,058 home visits to homebound patients of all ages residing within 40 miles of our offices, located in a medical office building adjacent to St. Joseph Hospital. The program has had 5,495 admissions since May 1973 through April 1977. Of this total, 3,777 admissions were patients over 65 years of age with 2,116 of these over the age of 75. Since July of 1976, we have admitted 1,638 patients to our service and have made 17,981 home visits. Our average census is 275 to 300 patients, and our average number of home visits per month ranges from 1,750 to 2,025. Our number of visits and length of service is 10 to 14 visits over a 6-to-8-week period. The majority of our patients receive home health services after hospitalization with only 10 to 12 percent of our referrals being made in lieu of hospitalization or without a recent hospital stay.

RANGE OF SERVICES

Our agency offers a wide-range of services through agency personnel, including nursing visits by R.N.'s and L.P.N.'s, home health aid visits, physical and occupational therapy, medical social services, and medical supplies. In addition to these usual services, we employ a psychiatric nurse, pediatric nurse, and respiratory therapist—L.P.N. We contract with a local speech pathology group and a patient education service, R.N., for home services and the hospital laboratory for lab tests. Mobile X-ray and EKG, as well as medical equipment, including respiratory therapy supplies and oxygen, are available to our patients through community facilities.

New Mexico has had a 31-percent increase in certified home health care programs in the last few years. There were only four programs when our program was started in 1973. However, we still have a long way to go. New Mexico is a very large State, but there is not much population.

The majority of our patients, 80 to 85 percent, are referred through one of the five home care coordinators employed by the three sponsoring hospitals or by agency nursing personnel who provide limited discharge planning in four other local, smaller hospitals. Through comprehensive discharge planning, appropriate referrals to our services are made by nurses well educated in the scope and limits of home health care. A carefully prepared written plan is delivered to the agency prior to the initiation of home health care.

Due to the acute and rehabilitative approach of our agency, frequent team conferences are held, often including the patient's attending physician. The program has been well accepted by the professional community and increased support has been evident in the growing number of referrals. In 1976, we received a small grant from the State of New Mexico, through the New Mexico Commission on Aging, in order to start a homemaker/chore service on a short-term basis to elderly clients in Albuquerque and Bernalillo County.

The homemaker is assigned to a family by a social worker after a home evaluation visit. Homemaker services are varied but generally

include light housekeeping, grocery shopping, meal preparation, and some personal care if needed. The homemakers are trained by our personnel in home management, nutrition, safety, and minimum nursing tasks. The service is usually needed on a temporary basis during a crisis and is free to individuals unable to afford a private homemaker. Funding for this program is limited; however, we have received notice of continuation of funds with a 12-percent increase for fiscal 1977-78.

NEED EXCEEDS SUPPLY

When I said a small grant, we have only three homemakers and the need really exceeds the supply. Many clients receiving this service would otherwise have to be placed in a nursing home. Since the homemaker service is considered custodial by medicare and medicaid, there is no Federal reimbursement available for this basic level of home health care. The elderly client's income is usually limited to social security and occasionally a small pension or savings; therefore, private sources of homemaker assistance are out of reach. To date, our limited experience shows that this vital service is provided for a period of 6 to 8 weeks per household during a crisis based upon professional assessment. State social service homemakers are available to welfare clients. There are at least 90 homemakers in Bernalillo County. Therefore, our service is designed for the client just above the financial limits for State welfare assistance.

Home health care is a complex of services which may be brought into the home singly or in combination in order to achieve and sustain an optimum state of health, activity, and independence for individuals of all ages, offering an alternative to unnecessary institutionalization, and at the same time assuring continuity of care through convalescence and return to health or toward a dignified death.

Our statement of philosophy, "Hospital Home Health Care Policy Manual," developed by agency personnel elaborates upon this basic concept.

[The material referred follows:]

We believe that all people have a need to care and be cared about, and to feel they have worth to someone and to themselves; that the patient has the need and right to choose to function at an optimal level of independence in the home and should have a voice in setting goals and in how they can effectively be reached; that the patient, family, and community have an integral responsibility in the patient's overall care and well-being; and that aging is a normal process of living and need not be a period of mental and physical deterioration.

We believe that hospitalized patients should receive the benefits of discharge planning to assist in the transition from hospital to community; and that when appropriate, we can provide a viable alternative to institutionalization.

We believe in the multidiscipline approach to patient-centered care in the home, recognizing and respecting psychological, social, physical, cultural, and spiritual needs; that all are entitled to the highest standards of care that we are able to provide; that the older person should be treated with respect and dignity and should feel that the staff is dedicated to restoring him to the fullest life possible; and that dying and death require supportive care and that patients should be allowed to die with dignity.

We believe that the home care program plays a major role in the community and has the responsibility to support continuity of health care.

We believe that continuing education is a means of improving quality of care; and that the hospital staff and the community should be educated in the services provided by home health care.

OUTLINE OF OBJECTIVES

Our general objectives based on this philosophy are as follows:

1. To educate physicians, hospital staff, patients, families, and the community regarding the concept of continuity of care, as well as the availability of home health care services which will provide such care.
2. To augment and supplement existing patient services of the participating hospitals by extending these services from the hospital setting into the home.
3. To promote the most effective and efficient utilization of hospital acute care beds through early and systematic evaluation of patients for post-hospital health needs; thus, lessening the length of hospitalization.
4. To promote continuity of care by providing skilled nursing, social, and therapy services, and laboratory tests for homebound patients who meet the eligibility criteria.
5. To air the physician in treatment, observation, and evaluation of the homebound patient, providing frequent communication to the physician.
6. To develop standards of patient care consistent with the agency's philosophy of total patient care through a team approach promoting patient/family independence in the home environment.
7. To provide for a system that will focus responsibility for the overall management and delivery of home care as well as coordination of home care services and resources within a centralized home care program.
8. To provide ongoing inservice education to home care staff continuously upgrading quality of patient care and promoting individual growth.
9. To periodically evaluate the quality of home care program through program evaluation, utilization review, nursing audits, and regular individual personnel evaluations.

National standards and peer review mechanisms have been developed and should be accepted by third-party payors of home health services. In addition to meeting standards, the home health agency must make a full range of coordinated services available to patients either through agency personnel or through agreements with existing community programs. This coordination of service is essential to the provision of continuity of care. In addition to the issues of quality assurance and coordination of services, the following recommendations are specific to medicare coverage of home health care and are supported by actual case histories from our files:

(1) A patient who demonstrates medical necessity for any one professional home health service should qualify for home health benefits for that professional service: specifically, coverage for occupational therapy or medical social services should be available without the requirement of skilled nursing, physical or speech therapy.

Mrs. A. is a well-known local artist who is 65 years old and married. In August of 1976 she suffered a stroke. She also has a history of cardiac disease; however, this had not inhibited her work. Her stroke left her paralyzed on the right side and she is totally aphasic. After a 6-week hospital stay, which included an initial rehabilitation program, she was discharged home. Her husband assumed the role of nurse and was not receptive to home health care at first. Both Mr. and Mrs. A. became frustrated due to Mrs. A's inability to speak. Physical therapy was ordered to attempt further gait training, but Mr. A. preferred to push his wife about in a wheelchair. Occupational therapy was ordered to assist Mrs. A. to relearn self-care activities and homemaking skills in her home environment. It soon became obvious that medical social service intervention was needed to help resolve the problems created by Mr. A.'s lack of motivation and Mrs. A.'s increasing dependency.

INTENSIVE REHABILITATION

The best solution seemed to be to discontinue physical therapy since this caused the most concern for both patient and husband. Mrs. A. was beginning to show interest in learning to manage her own care and homemaking activities through continuing occupational therapy, which is not a covered benefit without the need for continued physical therapy. All HHHC services were then discontinued as a professional reassessment of the current situation resulted in a plan for Mrs. A. to reenter the hospital for more intensive rehabilitation. After another 6-week period, Mrs. A. was discharged home with home health physical therapy and occupational therapy, again ordered by her physician. Mrs. A. seemed more motivated and did well with both therapies. She reached her maximum level with physical therapy which was then discontinued. Since she was

so highly motivated, occupational therapy was continued in order to further develop her activity skills such as personal care and homemaking, using various adaptive devices developed by the occupational therapist. Sixteen further visits were needed at a cost of \$368 which was partially paid by the family. Two additional "free" social service visits were needed to provide further counseling to the patient. Medicare paid for Mrs. A.'s home visits as long as physical therapy was needed. The total claim to medicare was \$568 over a 5-month period, with home health services being delivered for a total of 8 months for 24 visits.

Another example of a patient only needing occupational therapy is Mr. B., a 72-year-old married male. He has suffered from flaccid paraplegia (etiology unknown) for 6 years and has just recently been gaining the use of his legs. He is now able to walk with a walker and long-leg braces. All of his therapy has been rendered as an inpatient or outpatient through the rehabilitation unit at St. Joseph Hospital. Three occupational therapy visits were needed to evaluate adaptive equipment for his home in order to help Mr. B. become independent in his bathing and personal care activities. After being dependent on his wife for 6 years, Mr. B. was anxious to learn how to use this equipment and how to manage safe transfers to a bathtub. This type of occupational therapy is best provided in the patient's home since the outpatient department cannot duplicate circumstances that Mr. B. would face at home. Mr. B. demonstrated some anxieties and fears over this new equipment but with the careful coaching of the occupational therapist, he has become totally independent at home in his personal care activities. He continues a physical therapy exercise program with occasional evaluations of progress by the outpatient department of the hospital.

(2) The cost of prescription drugs and transportation when medically indicated should be a benefit of the medicare program.

Mrs. K. was a 79-year-old widow with a terminal diagnosis of cancer of the colon. She was diagnosed as having cancer in September 1976 and subsequently had a resection of her colon, resulting in a permanent colostomy. A program of long-term chemotherapy was decided upon by her physician. Mrs. K.'s sister came to live with her from Indiana. Upon hospital discharge, home health care was ordered to further instruct the patient and sister in the care of the colostomy. Mrs. K.'s condition was complicated by severe long-standing arthritis and diabetes mellitus, controlled by diet. Nursing visits were made daily for a couple of weeks until Mrs. K. was independent in her care and her surgical wound was healed. She still needed the chemotherapy injections twice a week. Since she was homebound and Mrs. K.'s sister didn't drive, the HHHC R.N. continued visits to administer the drug, which was delivered by a local pharmacy. Medicare did not help pay the cost of this drug since it was administered at home. The monthly expense for this drug alone was \$360. In addition, Mrs. K.'s other medications cost an average of \$40 per month. Mrs. K.'s income was \$326 a month from social security and a pension. If Mrs. K. had been able to get to the physician's office, medicare would have paid 80 percent of the cost of the office visit and chemotherapy. Our social service worker made several home visits to explore all possible resources but financial aid was not available due to her "high" monthly income and her total savings of \$1,500. HHHC services continued twice a week until January 1977 when it became evident that she was nearing death. Pain medication was increased and the R.N. visited daily for support and evaluation of the patient's worsening condition which she relayed to the physician. Mrs. K. died a peaceful and dignified death on January 13, 1977.

EXPENSIVE MAINTENANCE MEDICATIONS

This case is not only an example of the high cost of chemotherapy for cancer patients, but also demonstrates the need for some financial relief for the medicare patient's drug costs. Many of our patients must spend \$50 to \$60 per month for maintenance drugs such as cardiac medication, hypertension control medication, insulin for diabetes, and cortisone preparations for arthritis and chronic lung disease. Many other patients need special transportation to medical facilities or their physicians' offices yet this is only available through very expensive private sources if the patient has no family to provide this assistance.

(3) The provision of preventive care and medically indicated maintenance care should be a benefit of medicare extending home health care beyond the current definition of skilled nursing. Sometimes only the home health aide with biweekly nursing evaluation visits are all that the patient needs after intensive rehabilitation and therapeutic or restorative services are no longer indicated.

Mrs. G. is an 80-year-old widow with a diagnosis of congestive heart failure and arteriosclerotic heart disease. She is a very independent alert person at times and slightly confused at other times. She is hindered physically with a complicating diagnosis of osteoarthritis and is unable to provide her personal care needs adequately. Her heart condition causes occasional spells of shortness of breath and swelling in her extremities. Mrs. G. was first admitted to our services in June of 1974 after a stay in the hospital. Since then she has had eight home health care admissions, each admission following a stay in the hospital. Her physician is convinced that if HHHC nursing visits could continue once the patient has stabilized, frequent hospitalizations could be avoided. Even though the meals-on-wheels service is used and Mrs. G.'s son checks on her occasionally, her physician feels that biweekly professional assessments would be sufficient to completely maintain her at home. She is unable to get out to the physician's office so he makes home visits to her occasionally (at no extra reimbursement for the time involved), but he is not able to visit as often as needed. It seems that home health services of an R.N. and home health aide could certainly assist this patient to remain stable—the R.N. could notify the physician of impending problems, thus avoiding delay in action which results in another hospital stay, and the home health aide could assist Mrs. G. with her personal care needs, including some light housekeeping and meal preparation tasks.

Mrs. WALDEN. In addition to these specific recommendations, consideration must be given to the coverage of nurse-practitioner home visits to provide the highly technical assessments needed by patients too ill or disabled to get out to the physicians' offices on a regular basis. Payment should also be made available through home health agencies for physicians' home visits for doctors who are willing and able to make home visits and to create incentive for more home visits by physicians. Mental health nursing is a new benefit, through home health agencies, but only if the patient has been in a psychiatric institution and if the care plan is supervised by a psychiatrist.

I would like to suggest that other patients not yet ill enough to be hospitalized or not yet needing intensive psychotherapy could benefit from a psychiatric nurse or psychiatric social worker's home visits. Families could be helped to cope with the constant demands of caring for an ill or disabled person through the services of mental health nurses.

Nutrition services, including meals-on-wheels, should also be allowed as many illnesses require special diets as part of the therapeutic regime. The registered dietician is the person with the special skills and knowledge in diet therapy and these home visits should be a benefit under medicare. Respiratory therapy services are needed by many patients with chronic obstructive lung diseases such as emphysema. This is not now a covered benefit unless provided as skilled nursing, but I am suggesting the special skills of the respiratory therapist are needed, especially in the initiation and evaluation of therapy.

In summary, it is a difficult challenge to meet the needs of the chronically ill or severely ill person, regardless of his age. The difficulties of limited mobility, loss of income, unmet personal care needs, all compound the medical management problems. Lack of coordination of our health care resources and associated artificial barriers in various programs make the treatment and rehabilitation or medical care of the ill and disabled a very difficult situation. Medicare has been available for a little over 10 years, and it is time for evaluation with redirection of the available benefits. I am grateful for the opportunity to contribute to this examination of home health care as it is a meaningful and important contribution to the further development of the continuum of health care services.

Thank you.

Senator DOMENICI. Mr. Chairman, might I thank Judy for her testimony. I know how hard she worked preparing it. She runs a very large agency, and I think she has given us some examples and answered questions about how we can make these programs more flexible. Such reforms could save substantial funds or put them to better use, rather than triggering institutionalization when it is not needed. I appreciate her effort.

Thank you, Mr. Chairman.

Senator CHILES. Thank you.

Our next witness will be Mr. Robert P. Liversidge, Jr., executive director, Bath-Brunswick Regional Health Agency, Bath, Maine.

STATEMENT OF ROBERT P. LIVERSIDGE, JR., EXECUTIVE DIRECTOR, BATH-BRUNSWICK REGIONAL HEALTH AGENCY, BATH, MAINE

Mr. LIVERSIDGE. Mr. Chairman, members of the committee, ladies and gentlemen, my name is Robert P. Liversidge, Jr. I am executive director of the Bath-Brunswick Regional Health Agency, a medicare-certified voluntary nonprofit home health agency located in the mid-coastal area of Maine.

I am also president of the Pine Tree, Maine, Association of Community Health Agencies. I am on the board of directors and am chairman of the legislative committee of the National Association of Home Health Agencies.

The National Association of Home Health Agencies is, as its name suggests, a national organization exclusively devoted to representing agencies which provide health-related services in the home.

I am pleased to have the opportunity of speaking today about the topic "Health Care for Older Americans: The 'Alternatives' Issue," and do so in my capacity as executive director of my agency.

My remarks will be the product of my personal experiences as an agency director, and also, because of my extensive contact with others in the home care field through participation in our national organization, may reflect their concerns as well.

I would like to discuss several problem areas of concern to our patients and staff, and then describe three rather unique types of programs for senior citizens and others that our agency has developed.

In considering this topic, home health care is usually considered an alternative to hospitalization or nursing home care. Though it has been said before, I believe that care of the patient in the home should come first—and indeed the hospital or nursing home is the alternative.

Our agency serves a county and a half—a population of about 50,000—in an area which is mostly rural or at least small town. Our two largest towns have populations of 10,000 to 15,000 each, but most of our area consists of lobstering and fishing communities extending out on peninsulas into the Atlantic Ocean, or farmland which can be very difficult to reach in snowy Maine winters. We have a relatively high proportion of elderly population, and Maine is not a wealthy State.

We will make about 12,000 to 15,000 visits this year, with the full range of available services, such as: nursing; physical, occupational, and speech therapy; medical social services; home health aides; and homemakers. About one-third of our visits are by home health aides; most of the rest are by nurses and physical therapists. Physical thera-

pists, incidentally, are in incredibly short supply, at least in Maine, and I believe in other States. I believe this problem is as critical as the doctor shortage has ever been.

We have other, contracted services as well: early and periodic screening for low-income children; health screening for senior citizens; we have an agreement with the State to do all the public health nursing for Bath and Brunswick; we have a grant from the Maine Lung Association to visit patients with lung disease; and several patient education programs, as well.

I want to mention the above to make the point that, unlike some home health agencies, we are striving to be an umbrella-type agency for our relatively small, but dispersed, population area. Although home health is the most important part of our services, senior citizens and others look to us for many other health services. Indeed, we often receive calls that put us in a situation of being an information and referral agency as well.

One of the problems our agency faces—a barrier to even more effective utilization of our agency—is that even without all these additional health programs the tremendously complex tasks of dealing with variations in eligibility for our patients under title XVIII, XIX, XX of the Social Security Act, and titles III and VII of the Older Americans Act, can be disheartening if not overwhelming.

ALL PATIENTS ACCEPTED

Our agency has the specific policy of accepting all patients, regardless of their ability to pay. Basically, if the patient is old enough and sick enough he is covered under medicare; if he is poor enough medicaid will pay; we have a small amount of Older Americans Act funds to help with costs of caring for chronically ill elderly in their homes; a few insurances will reimburse for home care, all with varying requirements in basic policies, major medical components, prior hospitalizations, and so forth. We go to United Fund and to 14 separate town meetings—a unique fact of local government in Maine—asking for appropriations to pay for those needing service, not covered, and unable to pay; and we have a sliding scale of fees for the remaining 10 percent of our patients.

[A table follows:]

Income percentages, Bath-Brunswick Regional Health Agency, 1976

Home Health :	
Medicare A and B-----	43
Medicaid-----	14
Central Senior Citizens (OAA)-----	6
Self-pay-----	1
Municipal and United Way :	
Municipal appropriations (14 towns)-----	11
United Way (2 United Ways)-----	6
Other :	
Medicaid (EPSDT)-----	9
Lead poisoning detection contract-----	1
Senior citizens health contract-----	1
Maine Lung Association grant-----	2
Davenport Foundation (homemaker)-----	5
Miscellaneous-----	1
Total-----	100

¹ Use distributed among home health, health screening, patient clubs, and maternal and child health programs.

The problem that this network of programs has created is, to some extent, one of needed services that are not covered by some of the programs. For example, medicare will only pay for assessment visits if the patient is, in fact, admitted as a patient; services often at a lower skill level, for the chronically ill, are not included.

However, the problem is also one of lack of "crosswalks" from one program to another. Realignment of these programs to make them more consistent with one another would make possible the more efficient utilization of available dollars.

The fact that we are asked to collect different data in different forms for different reports for different programs is in itself an expensive aspect of administrative overhead. My education and experience has included a master's degree in business administration and 7 years' experience in industry, and yet even I find problems of cash flow—we have to wait up to 9 months for payment of some medicaid claims, and 3 years for settlement of our medicaid cost report—very difficult. I can appreciate the problems of other agencies with no one on their staff who has business management expertise.

I know in some areas of the country the relationship between agencies and their fiscal intermediaries has been strained at best. I must say in Maine this is not the case. Our agency's relationship with Maine Blue Cross is very satisfactory. I bring this up because there has been discussion of legislation establishing regional intermediaries or a national intermediary for home health agencies. While some agencies elsewhere may welcome this change, we would not.

As a home health agency director, I am keenly aware that there are few controls on entry into the field by new home health providers, and that medicare reimburses on the basis of the lower of cost or charges. I am concerned that competition will be brought about, as a consequence, that will generally raise costs, fatten administrators' wallets, and continue to leave unserved those who are not covered by medicare or other insurance.

INCENTIVES FOR NURSING HOMES

I am particularly distressed by those who advocate incentives for nursing homes to enter the home health field, for I feel that this is clearly a conflict of interest situation and, frankly, I personally have reservations about the capability of many nursing homes to provide care of the same quality that most home health agencies exercise.

One answer to this problem is the inclusion of home health in certificate of need regulations, and, in my opinion, revision of Federal and State certificate of need regulations should be the No. 1 objective of the home health care field. I think it is, and I hope it will be acted upon.

I might depart from my prepared statement to say another important area is that of standards, and I certainly applaud the effort of Congressman Cohen to establish a set of uniform, objective, measurable standards in the home health care field.

As I had mentioned earlier, our agency has chosen to provide multiple services for those in our area. Before I briefly discuss three of these programs which may be of interest to you, I should emphasize that we look at the things we can provide as falling into three areas: bedside care for the sick, prevention of illness and disease, and patient or public education, for lack of a better term.

We have found that, while many resources are available to us in caring for the acutely ill at home, we cannot say the same for being able to pay for home health care for the chronically ill or to prevent recurrence of illness of institutionalization. It is a continuing theme that our health care system is crisis-oriented, and my experience leads me to believe that in spite of the best intentions of our staff, this is where the reimbursement comes from in home health care as well.

In our agency, we are trying to do something about that. We have begun several programs for senior citizens that are educational and preventive in nature, and I would like to speak about three of them.

First, we began a program of health screening for senior citizens 2 years ago. We hold screening clinics in all the towns we serve, and have developed a mailing list of as many elderly as we can find. Through the mailing list, we announce dates, locations, and what tests will be done. Blood pressure, glaucoma, diabetes, oral cancer, routine foot care, and anemia are the primary tests, and we have literature available on arthritis, diet, and lung problems, among others.

We have a short intake form, making sure to get the name of the person's physician, and allow a few minutes for the person to speak with one of our nurses about any health subject they want. As elderly persons usually only go to a doctor when they feel really sick, and so often don't want to bother him with something they feel is trivial but may not be, this part of our program is very important and very revealing.

Although some area physicians were skeptical at first—a few even hostile—they are not now. Because of the high incidence of glaucoma symptoms we discovered, another ophthalmologist moved to Brunswick. We actually added patients to physicians' practices rather than taking them away, as some had feared. Thanks to partial funding from our local senior citizens' programs, United Way, and municipal support, we have kept this program going, not only the clinics but the extensive followup that we commit ourselves to when we encounter a suspected problem.

The important thing to note is that of the 600 to 1,000 persons we see each year, between 30 and 40 percent have at least one suspected health problem which should be seen by a physician.

The second program I would like to mention is the grant we received from the Maine Lung Association for, appropriately enough, Project L-U-N-G—Living Usefully with Nursing Guidance. The project paid for half the salary of one of our nurses, who adapted programs on care of persons with lung disease which she received from western Massachusetts and Arizona. She has been seeing about 25 patients over the past year at home, each with lung disease, including five of whom are severely ill. Let me give you an example of the results:

Mr. B., age 72, had been in and out of hospitals with his respiratory problem for years. In the 6 months prior to our admitting him, he probably spent half his time hospitalized. Indeed, he had reached the point that his confidence could be maintained only in the security of four hospital walls. Our respiratory nurse began visiting Mr. B., and did a number of things: Instruct him on proper cleaning and maintenance of his breathing equipment; taught him more about his disease and what to do about it, particularly with regard to diet, exercises, and his environment; and brought his confidence and security up to the point that he did not need to be hospitalized.

SAVINGS FROM \$5,000 INVESTMENT

Indeed, in the last 9 months Mr. B. has been in the hospital only once, and that for a nonrelated problem. In fact, the bottom line for this program is that, estimating very conservatively—and our project is still going on—the Maine Lung Association's investment of \$5,000 has saved at least \$50,000 in hospitalization among the patients we have seen.

Third, we have started patient clubs for persons with ostomies, co-sponsored by the Maine Chapter of the American Cancer Society, for persons with breathing problems, co-sponsored by the Maine Lung Association, and for diabetics. Our nurses assist with mailings to members, getting speakers, and provide the continuity for club activities, and I might mention getting some of the patients to attend the programs as well.

We feel the opportunity of patients with these problems to learn more about their diseases in a group setting with others with the same problem has been invaluable to them. This has provided club members with others to interact with socially and to call upon if they need help.

I have discussed these activities because we believe we have successfully demonstrated and are continuing to demonstrate some specific programs in prevention for senior citizens and others that can be successfully carried out by home health agencies who wish to broaden their horizons. With few exceptions, they are not reimbursed by any sort of State or Federal program, and they should be. And each represents one more way we can assist older people and others to stay in their homes, thereby avoiding the alternatives—institutionalization.

In summary, I have outlined several barriers to more effective delivery of home health care—fragmentation, cash flow problems, inappropriate competition, and unwillingness on the part of third-party insurers to invest in preventive-type programs even though they can be shown to work.

Before I end my statement, however, I would like to make one additional point. Home health care is still struggling for visibility. When Mrs. Carter invited representatives from the field of aging and long-term care to meet in the White House on May 10, home health care was not included. It is a frustrating thing to be doing so much good and to remain so invisible, and I appreciate being invited here today to bring some of our very valuable programs to light.

Senator CHILES. Thank you very much for your statement.

The last witness on our panel will be Mrs. Ruth Breslow, Rockville, Md., executive director of the Jewish Council for the Aging of Greater Washington.

Mrs. Breslow.

STATEMENT OF RUTH W. BRESLOW, ROCKVILLE, MD., EXECUTIVE DIRECTOR, JEWISH COUNSEL FOR THE AGING OF GREATER WASHINGTON

Mrs. BRESLOW. Thank you, Mr. Chairman.

I am honored to be here today to take part in this important discussion of alternatives to institutionalization for older people.

The Jewish Council for the Aging of Greater Washington is a

locally based multiservice agency serving senior citizens, and I might say not a health care organization per se. We are a private nonprofit organization supported in part by the United Jewish Appeal Federation of Greater Washington, and we operate throughout this metropolitan area.

Our principal charge is to assist older people to remain in the community as contributing members of society. We operate a minibus transportation system—several of our vehicles have been obtained through the Urban Mass Transit Administration; a title VII Older Americans Act kosher nutrition program; a title IX Older Americans Act senior aide project; a geriatric day care program; and a number of other services. All of these programs can broadly be construed as preventative of premature institutionalization by assisting people to remain in their own homes.

There comes a point, however, for a segment of our older population, where remaining in their own homes with whatever battery of supportive services which can be provided is simply no longer feasible. For one thing, an individual may not have a home any more. He may be residing under strained conditions with an adult child or be shuttling back and forth among several children with no space to call his own. He may be living in his own home, but be in a continual state of anxiety about being alone.

Many other factors may contribute to his inability to manage on his own, yet he does not need nor want a nursing home. For this person, new housing options must be developed which provide him with companionship and assistance in the activities of daily living as needed, but permit him to retain his sense of autonomy and dignity.

Over the past 2½ years, our council has developed such a program on a pilot basis. We now have 8 leased 3-bedroom apartments with housing for 24 residents—18 women and 6 men. All our residents have some degree of physical or mild mental impairment, but are able to take care of most of their personal needs and manage their own medications. They range in age from 62 to 96, the average age being about 78.

We provide part-time homemaking services, 20 hours per week in each apartment—in other words, one homemaker serves three people in each instance. The homemaker shops, prepares, and serves the main hot meal, and leaves a cold supper ready, if requested. She also escorts residents to doctors if necessary. An MSW social worker directs the program—Mrs. Judith Shaffert, who is with me today—assisted by a part-time caseworker. One of them meets at least weekly with residents in each apartment to smooth out any difficulties which may arise. They maintain contact with families, interview prospective residents, supervise homemakers, and help families develop alternative care plans when our program no longer is appropriate. Their presence is crucial to the smooth functioning of the program.

Each resident has his own bedroom and may furnish it as he chooses. He sometimes contributes furniture to the communal living areas as well, but no single individual furnishes the entire apartment. We provide wall-to-wall carpeting as a safety feature, and fill in the gaps with donated furniture and linens.

We provide minibus transportation to senior citizens' activities twice weekly and several times a month to an evening movie or cultural

event. Residents meet together twice weekly in the restaurant-social hall in the building. They are engaged in a variety of stimulating volunteer and educational activities. There are also innumerable informal small get-togethers for cards, bingo, or just friendly chats.

NOT SEGREGATED BY AGE

Our residents have the advantage of being able to establish close peer relationships without being segregated by age since they live amidst the hubbub of a busy apartment house with a polyglot population. There is a synagog virtually next door and a nearby shopping center, so they certainly don't feel they've been put on the shelf.

They have developed a real esprit de corps—a family feeling which is heart warming to see among these formerly lonely and insecure individuals. Family feeling grew so strong between two residents that indeed we had one wedding. The happy couple took a one-bedroom apartment in the same building, and we continued to provide some supportive services to them until the husband's recent death. We are still involved with the widow.

This approach to housing has many administrative advantages. There is no capital investment, although startup costs are about \$1,000 per apartment. All our apartments are located in one high rise building and this simplifies delivery of services. Our present plans are to increase the program by two apartments. But we do not wish to grow too large and would like to experiment with other models, perhaps in other locations.

Our operating costs are about \$395 per person per month, which is approximately one-third the cost of nursing home care in our area. The cost effectiveness of this type of program is self-evident, but the human dividends are immeasurable.

Since many of our residents cannot afford the full fee, this program has always operated at a deficit, which our agency has picked up. We have this year been aided considerably by section 8 rent subsidies, which now provide for seniors in congregate living as well as individual apartments. Twelve of our residents receive section 8 subsidies, averaging about \$80 per person per month.

HELP FROM SHELTERED HOUSING PROGRAM

We have also been aided by Maryland's unique sheltered housing program, which provides for further subsidy for food and services to seven of our residents.

I might point out that some qualify for one program and some for another. Each program has differing requirements. But with rising costs, we still anticipate a considerable deficit and this is, of course, a limiting factor on our growth.

The relative simplicity of this group living concept leads one to wonder why it has not been adopted on a more widespread basis. The poster I have here is entitled "I'm very happy for Mother; she just moved into a commune," and is furnished by HEW. When you track it down, however, there is no information available from HEW or very little on communal living for older people.

When the New York Times article,¹ which I have attached to this

¹See p. 40.

statement, appeared, it generated a great deal of interest and we received requests for detailed information from individuals and agencies in communities across the country. We even heard from a native

THE NEW YORK TIMES, SATURDAY, SEPTEMBER 20, 1975

Apartments for Elderly: Helping Hand, Not a Nursing Home

By LISA HAMMEL

Special to The New York Times

SILVER SPRING, Md.—“We lived in D.C. in a beautiful house with a beautiful yard. We had a store, a grocery store. But then my wife got sick,” said Louis Eisenberg. “She died in 1974.”

Mr. Eisenberg sighed and looked away.

“I was 51 years happily married. My wife wouldn't let me butter a piece of bread for myself, maybe I wouldn't put enough butter on if this hadn't come up”—he waved his arm around his apartment—“I tell you frankly, I would have done away with myself. Of course, I'm lonesome for my wife. But otherwise, this is a heaven.”

When Mr. Eisenberg, who is 77, gave voice to these mixed emotions, he had been living for seven months in a modern high-rise here, in a spacious apartment he shared with two other widowers. The three of them, along with a small group of other men and women, were participants in a special housing program for the elderly.

The program is run by the Jewish Council for the Aging of Greater Washington, a private social service agency, and the plan now serves six men and nine women, aged 65 to 88.

A New Arrangement

But things changed recently for Mr. Eisenberg. The situation he said virtually saved his life has also now suffused it with romance: Last month, Mr. Eisenberg and Bessie Cutler, 64, one of the women residents in the program, were married. They still live in the same apartment house, in a one-bedroom apartment, but are no longer actually part of the program.

The program of housing combined with supportive services was begun almost a year ago by the agency. Last October it began renting apartments to help a small fraction of the elderly people in the area who are no longer able to live alone, yet could not live with their chil-

dren, often because they were not made welcome.

“The apartments are for most of them,” said Ruth Breslow, executive director, “would be a nursing home. Or barely getting along in a little hole in the wall.”

The apartment sharers are well aware of the lack of viable alternatives.

“You lose your temper at times,” said Sadie Weinberg, speaking of occasional differences among her apartment mates, “but I always tell them, ‘You know, you have to get along. You have no place else to go.’”

“I spent a lot of time in hospitals and nursing homes,” said Sara Stein, who moves about briskly with a walker. “And nursing homes are out. I told my son, if they put me in another one, they'll take me out in a box. ‘This is my home now,’ she said pointedly. “And nobody will chase me out of here.”

The council presently has five apartments in the Eldorado Towers, once a luxury high-rise but now a highly integrated complex filled with people of all ages. Each council apartment is occupied by three residents, all of the same sex and, wherever possible, of similar background. The agency plans to open a sixth apartment soon.

Private Bedroom

Each apartment has three bedrooms, so that every resident has his or her own room, and a shared living room, kitchen, dining ell and a balcony that overlooks lawns, woods and tennis courts. The average rent for each group is \$316 a month.

“The beauty of it is that there is no capital outlay,” said Julius Sankin, president of the council, who is a builder and real-estate operator. “The apartments are rented as the need arises.”

The residents pool their incomes, which come mostly from Social Security, and keep \$25 a month for personal expenses. The difference between the pooled fund and

the total cost of running the operation, which includes everything but medical care, is made up by the agency, supported entirely by contributions from members.

In terms of the price of institutional care, the cost for this kind of housing alternative is modest: a yearly gross expense of \$4,000 for each resident, of which the residents themselves pay more than two-thirds.

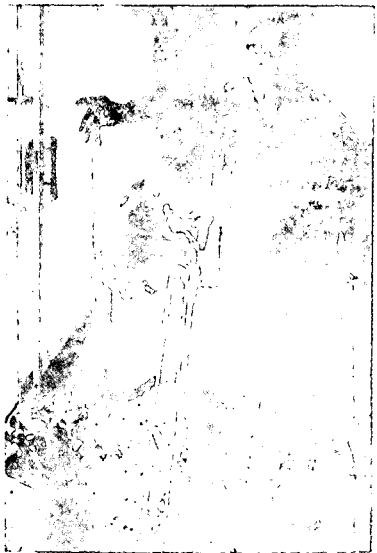
“A nursing home in this area would cost about three times that,” Mr. Sankin said. “It costs us a net average of only about \$900 a year per resident.”

There are no hard and fast residency or income requirements for the residents,

but they must be at least ambulatory within the apartment.

The services of a homemaker, who markets, cooks and oversees day-to-day running of the household, are provided to each apartment five days a week. A house-cleaner comes to each apartment one day every other week, and a social worker, assigned by the agency to the housing program, comes around on a regular basis to iron out problems, help with benefits, make peace and the like.

The agency's minibuses take the residents on outings that include plays and mo-



Sara Stein in carpeted living room of the apartment she shares with two other women.



The New York Times/David Vick

Arthur Herschdorf stands on balcony of the high-rise apartment house in which he lives.

vies, activities at community centers, religious services, visits to physicians, shopping, and sightseeing tours.

"But we try not to give more service than they need," Mrs. Breslow said. "We don't want to develop dependency when it isn't there."

The residents, most of whom were living with children after being widowed or becoming disabled, are all Jewish, and are either European-born or first-generation Americans. Most come from working-class backgrounds.

Their disabilities are a cross-section of ailments afflicting the elderly: heart disease, arthritis, diabetes, osteoporosis, falling vision, Parkinson's disease, hearing impairments. But perhaps most important, they were also suffering from that most common of all gerontological disorders, loneliness.

"After my husband died," said Esther Schudroff, who had lived in New York, "I felt very lonesome and isolated. I have a lot of friends in New York that are widows and live by themselves, but I couldn't do it. So this was a good solution for me."

Mollie Kurasc also came down from New York, to stay with a daughter temporarily after she'd been mugged and robbed several times.

"You don't know what it meant to be so scared you couldn't open the door," she said, as she, Mrs. Schudroff and their third roommate, Rose Lewis, sat in the sun-filled dining area eating an early dinner.

"Sometimes families can't do as much for you as this agency does," said Mrs. Lewis, who was the pioneer resident. "And the greatest advantage is not being alone. If we feel like we're tired

of each other, we can go to our own rooms. But when we want to talk to somebody, we can just open our doors—and there's always somebody there."

Part of Society

People in nursing homes, Mr. Sankin believes, feel an anonymity and isolation that "cannot be disguised, no matter how noninstitutional you try to make it. But people in an apartment feel that they are still part of the community, part of society."

To Arthur Herschdorf, who lost his leg in an accident and likes to joke about his array of walking aids, being able to feel like "a worthwhile human being" is a major consideration.

"Here you don't feel that because you've reached an age or because of some infirmity, you're being thrown on the ash heap. The most important thing is for a person to maintain their dignity."

Sara Stein would like to see the plan spread around the country.

"It's one of the best things they could do to help people in their later years—so they could be happy for the rest of their lives."



JEWISH COUNCIL for the AGING

OF GREATER WASHINGTON, INC. 6123 Montrose Road, Rockville, Maryland 20852
phone (301) 881-8782

American group in Kodiak, Alaska, who stated that they had similar problems.

Syndicated columnist Peter Weaver has written about this and similar programs on several occasions, and each time has been flooded with queries from people desperately seeking housing alternatives such as ours.

The Council of Jewish Federations and Welfare Funds held a seminar last September 1976 on the subject of "Options in Living Arrangements for the Elderly," at which five models of small-group housing, including our program, were presented. I have left several copies of the proceedings of this conference with your staff. Here, too, much interest was generated and I know of perhaps 10 or 12 agencies which have since begun projects.

Nevertheless, the number of small group homes which have been developed is miniscule in relation to need. In view of the potential savings of public funds, I would urge this committee to concern itself directly with facilitating the growth of this type of housing alternative.

RECOMMENDATIONS

Among the steps which I would urge are :

(1) Establishment of a clearinghouse where interested groups could garner information and guidance on setting up group homes. Because this type program combines housing and services, it seems to fall between the cracks of HUD and HEW. I recall that each agency referred me to the other when I was seeking assistance for our program. Therefore, I think such a clearinghouse might well be situated in the Administration on Aging.

(2) The Administration on Aging should also be directed to fund model projects around the country, with suitable research and evaluation components, so that the positive impact on peoples' lives of the group home approach as well as its cost-effectiveness can be documented.

(3) An effort should be made to simplify and coordinate Federal, State, and local regulations which were not written with group homes in mind, and present a discouraging obstacle course to agencies and groups which seek to sponsor group housing.

(4) Whatever actions are taken, they should be supportive of locally based, private, nonprofit agencies and organizations who have the will and the skill, if not always the means, to develop small-scale, innovative, group housing programs.

In the words of the eminent Scottish geriatrician, Dr. Ferguson Anderson, whom I recently had the privilege of hearing discuss aging programs and services in general, we should "think small on a large scale."

I am grateful to have had the opportunity to appear before you to present my views and those of the Jewish Council for the Aging on the important issue of housing alternatives for older people.

Thank you.

Senator CHILES. Thank you very much.

Doctor, you made it clear that you treat some 30 elderly patients on a regular basis, in their homes, according to the article that was in the New York paper. Where would these people get treatment if you were not treating them and, after you treat them, can you turn them over to a home health care agency or personnel?

Dr. FRIESS. I get most of my help from the Visiting Nurse Association. It came from the home care program at New York Hospital and from various church groups.

I usually don't turn them over; I usually stick with them until they either get well or die—usually the latter.

Senator CHILES. In the same article, it also says that you believe medical students and interns need the direct experience of dealing with older persons. Is that something that can be taught at medical school, or does it have to occur in everyday prior accommodation?

Dr. FRIESS. I think a direction can be taught, but I think the important thing is in the selection of the students for medical education.

I think there has been a tremendous amount of emphasis on brilliance and intelligence, but I don't think there has been nearly enough emphasis on human attitudes.

I think this extends also to the house staffs of these various institutions where, I think, the attitude is there is not much you can do about this older person; therefore, they go to the bottom of the admissions list. In a particular hospital that I am associated with, the house staff has a great deal to say about who can and who cannot be admitted to the provision services, but there are many, many exceptions to this.

There are many house officers who are oriented toward the elderly but, by and large, they are in the minority rather than in the majority. I feel that house officers should be taken out into the community and should get part of their education there. The attending doctors should supervise them and make home visits with them, but this has not been implemented.

I have been saying this for a long time.

Senator CHILES. Thank you, Doctor.

We are delighted to have Senator Percy with us now. He was not here when we started. He has long been interested in this subject of home health care.

Senator, I hope you will join in any questions.

STATEMENT BY SENATOR CHARLES H. PERCY

Senator PERCY. Thank you very much.

I would like to say how sorry I am that I have had conflicts all morning, but I have carefully gone over your testimony. Certainly this testimony today, Mr. Chairman, will be, I think, of tremendous value in evaluating the alternatives that Senator Moss and I have been exploring through the years. I am glad that it will be available now for the staff and for the forthcoming report that the committee will be putting out. Certainly we are very grateful for the appearance of all of you here today. I am most impressed with what has been said.

I would just like to ask one question, if I may. On the problem that we have of coordination of home health programs, it seemed as though the theme that ran through much of your testimony has been the fragmented nature of the present home health programs and how they differ under titles XVIII, XIX, and XX of the Social Security Act and title III of the Older Americans Act.

Sometime during the course of your comments, I think we would appreciate very much any advice you have as to how, based on your experience, the programs can be coordinated in a better fashion. Maybe this is a good time to give us that advice, or if you want to submit it to us in writing, it would be appreciated, I know, by the members and by the staff.

How, for instance, does a person go about finding out how to get a home attendant? In other words, where does a family of an older person go to get that kind of assistance?

"UMBRELLA" COVERAGE

Ms. KINoy. If I might respond to that, sir, what has to happen, it seems to me—and I would assume that many of my colleagues here

would concur—is that Federal legislation needs to be enacted under which various types of home care arrangements are put forth so that it would be possible to include within one umbrella-type of Federal legislation something as specialized as a home health aide and as limited as a chore service.

I do not think it would be difficult to develop a package which would include the various disciplines and also the specific planning, supervision, and training necessary to all of these services.

Senator PERCY. I was struck when I was writing my book, "Growing Old in the Country of the Young," by the fact that there was no single place I could go to get information on various programs—no place that an older person or their family could go to get a centralized source of information. So, after a lot of research, we compiled and put in the index of the book a guide to such services for anyone, no matter where they lived—phone numbers, addresses, and so forth. However, my book was published in 1974, and such guides, of course, go out of date.

Is there now a Federal agency or other centralized source where one can go to get information, advice, and counsel?

Mrs. BRESLOW. I believe the area agencies on aging all have referral services. Their effectiveness varies. In our area, we deal with five jurisdictions. There is a great variation in the skills and knowledge of the different area agencies, but this is the spot where guidance is supposed to be available.

Senator PERCY. Mr. Chairman, I want to thank you very much indeed for your chairing these hearings and the deep interest that you have taken through the years in this problem.

I am sorry that I have to come late and leave early, but I know that all of the members of the committee will value very greatly this testimony. We deeply appreciate, again, your being here today.

Thank you, Mr. Chairman.

Senator CHILES. Thank you, Senator Percy.

Mr. Liversidge.

Mr. LIVERSIDGE. I just wanted to mention two things which may help agencies get more patients. One is the fact that, as I understand it, at the present time medicare will not reimburse for advertising costs for agencies. My suggestion would be that if a modest amount of an agency's budget could be used to do some advertising in newspapers about the services that are available, other than just public service television ads that don't always appear at the time that people are watching, this might help educate the public as to what services might be available.

DISCHARGE PLANNING

The second thing is the possibility of a more aggressive discharge planning program in hospitals, wherein representatives of home health agencies are a part of the discharge planning committees in the hospital. This is true in our area, but not in many others.

I know in our own case this has resulted in tremendous increases in patients.

Senator CHILES. We saw in Florida some aggressive discharge planning among the nonprofit health care agencies; in fact, they ran over each other in some instances, with two or three making visits to sign

up the patients. They were actually paying fees to some of the nurses and people who were working in the hospital for leads that led to a patient.

They gave trips, some of them, to the Bahamas. So they had some very, very aggressive discharge planning in order to sign up people.

I understand the point that you are making, and I think we need to do some of that. Our problem was that some of these people whom they were signing up did not need all of the services that they were rendering to them. We find that they were giving some services to people who were comatose. We began to worry a little about some of the services that they were getting.

You mentioned the need for a local agency to bring the different programs and regulations together. Do you think the Federal Government should encourage this or, if the Federal Government gets into it, are we going to have another layer of bureaucracy that you have already said you were concerned about?

Mr. LIVERSIDGE. Would you repeat that again?

Senator CHILES. You mention in your statement the need for a local agency to bring the different programs and regulations together to try to coordinate them and have them together. Do you want the Federal Government, that has created all these different programs and different regulations, to try to encourage that, or how does that come about?

Mr. LIVERSIDGE. I am not sure I have the answer, and I don't think anybody does. I do think that some of the reporting systems within, for instance, our agency requires the preparation of many different types of cost reports for each of the various organizations from which we receive funds. They should be coordinated in some fashion so that we are coming up with the same set of data instead of, as another witness said, continually pulling different kinds of files for different people for different purposes. It takes a tremendous amount of time to do that. I think that will be a good place to start. I think many of the benefits for recipients are there; it is just a question of tying them together in some fashion.

SCREENING OF ATTENDANTS?

Senator CHILES. Ms. Kinoy, I have some concern about the attendant that is being hired by the elderly persons themselves, and whether they have the expertise and the wherewithal to know what they are getting, and then whether they are going to be dominated by that person later. What kind of screening do these attendants go through to see that they are at least from the pool, of which they are beginning to hire people—or is there a pool? Can it get into the situation, as you said, where an alcoholic hires another alcoholic, or where some person just sort of preys on the elderly?

I understand, in some stories, that some of these people are aliens that are not even naturalized or seeking citizenship and don't speak English.

Ms. KINOY. I think there are several answers to your question. Several parts of the question have been answered. I think that, in the long run, the only way that this really could take place satisfactorily is for one agency to do the hiring, the training, and the screening of these persons, and then the agency would create a pool from which the patient could—

Senator CHILES. I think that is how it is done in New York now.

Ms. KINOY. In New York now, where there are home health aides, homemakers, or housekeepers, this is done. But this is not done in the home attendant program, and I would think—

Senator CHILES. How is that home attendant program funded now?

Ms. KINOY. That is funded primarily by medicaid title XIX and title XX, and it is important because it serves a totally different population of the long-term chronically ill patient.

It seems to me that where a person only speaks Hungarian or only speaks Greek, or whatever, the problem is, if such a person can find his or her own home attendant, that is wonderful. But that person then should be made a part of the roster and should be screened and trained and made available to other persons of the same ethnic group.

Senator CHILES. How does the process work now under the attendant program in title XIX and title XX? I mean, how does the person get signed up?

Ms. KINOY. Well, the way the person gets signed up now is by a very complex procedure. Let's say the patient is hospitalized. The patient then is sent home. The department of social services then makes an evaluative visit and determines that the patient is ill and is at home. Then they have to make a determination that this person is eligible for medicaid. Then there is a whole procedure for signing this person up which takes an endless amount of time at which point the individual or the family is told: "Now go out and hire a home attendant." Then, if there is someone on the roster who is available, they select somebody from this roster.

Senator CHILES. They did have a roster?

Ms. KINOY. We are beginning to develop one in some of the counties. I must say that we are tremendously concerned about this, as you are, and we are trying to make sure that the persons on this roster are now starting through some kind of a screening procedure. I hope that in the next year or so this really will take place.

Senator CHILES. This is a growing program in New York, as I understand it; right?

Ms. KINOY. Yes; I think it is a program, however, that eventually is going to be well controlled. On the one hand I agree with you that it is necessary to have evaluation and controls and a real way of having a very sharp handle on this program. On the other hand, I would not want to have it as terribly limited as the medicare program, which eliminates many persons from benefits.

I think we have to be very careful as we try to regulate this new experimental program that we don't, once again, keep out people whom we have finally been able to draw into it. Some persons, for example, who are in this program now are those who are feeble, long-term older persons who may not have any one of those specific illnesses that title XVIII pays for.

Senator CHILES. I think that is true. I think on the one hand we don't want to keep those people from getting services, but we have to put some kind of control on the services that they are getting and see that we have accountability for that.

Ms. KINOY. Absolutely. Right.

Senator CHILES. I understand that New York is not the only State

in which this is growing—that this is actually growing in a number of other States as well.

Ms. KINOY. That is what I understand.

I would like to ask a question of the committee, if I might be so bold.

Senator CHILES. You may try. [Laughter.]

Ms. KINOY. There was disagreement in the testimony about care in the home emanating from a nursing home, and I was wondering what your thinking was about that, Senator.

NURSING HOME-BASED CARE?

Senator CHILES. Well, I think what we are trying to determine is, if you are beginning to experiment, where would you start? I think that nursing homes certainly could give some outside care, but it seems there is a built-in conflict when a nursing home, being the sole agency, talks about outside care, especially if it is a for-profit nursing home. That would be the only thing that I would be concerned about if they were in charge of conducting the experiment.

There might be other places where you would house your out-patient geriatric treatment, but you just have to determine that there is not a bias there. That would be my only concern.

I noticed, Mrs. Walden, an article in a recent Parade magazine that said you thought that your services save the U.S. taxpayers a fortune, and it quoted you as saying nursing homes in your area cost \$21 to \$35 a day, but you charge \$18 a visit and average no more than one or two a week for only a few months. Is that an accurate statement of what you have been able to do?

Mrs. WALDEN. The gentleman that wrote the article had some preconceived ideas about home health care. There has been another comment made by a committee member on the cost of home health care. When the author came I was in the process of doing a detailed study of cost of home health care by diagnosis. In other words, I have categorized 19 different conditions and have analyzed how many are male, how many are female, the source of fee payment, the age breakdown, the referral source, the length of stay, the number of visits, the reason for discharge, and the types of visits by the different disciplines that we offer, to arrive at a total number of average days per care—not number of visits—then the number of visits within those dates, and then the actual cost for our service.

This study is an ongoing one. This will be a year accumulative and then next year the same study will be repeated. We hope to use the data in planning for predictable "length of stays."

Our program, though, is somewhat different, since the home health service is hospital-based and a little more acute-care oriented—more rehabilitative oriented—and I think that one or two visits a week is somewhat low.

Senator CHILES. Mrs. Breslow, your service, as I understand, does not provide physician care.

Mrs. BRESLOW. No; it does not.

Senator CHILES. So each patient must have a private arrangement with a doctor?

Mrs. BRESLOW. Yes.

Senator CHILES. Do you have evidence to suggest that this group living in any way reduces the need for medical attention and even institutional care?

Mrs. BRESLOW. Well, I cannot say for medical attention. It seems that our people go fairly regularly to doctors, but we have not studied that particularly. I can speak to reduced need for institutionalization. We have people who were waiting to go into the home for the aged but, provided with this alternative, decided it was much more appropriate and are happy remaining in our program.

In terms of cost to the community, of course, it is much better to keep older people in our program than it is to put them into homes for the aged, but our residents have made that choice because they have found a satisfactory living situation, not necessarily because of financial considerations.

Senator CHILES. In your apartments you are only providing for ambulatory patients. What happens when one of them becomes bedridden?

Mrs. BRESLOW. We have not had that happen per se, but they would have to leave our program. We do, on occasion, have a nurse's aide come in for a few days when somebody is ill to give some additional care. But if it becomes anything more lengthy, an alternative plan must be made. Our social worker assists in this. We cannot accommodate people who are wheelchairbound or bedridden. We will hold a place, up to about 6 weeks, for someone who is temporarily hospitalized or in a nursing home.

Senator CHILES. I am going to have to leave. I think we will continue, with the staff asking a few more questions, because we do have some more questions we would like to put to you so our record can be completed, if you all could stay just a few minutes longer.

HEW WITNESSES TO TESTIFY

I would like to announce that some question has arisen as to whether we will hear HEW witnesses on Wednesday or whether we will have to postpone that hearing in order to get adequate representation from HEW. We will have to make that decision probably by tomorrow as to whether we will have a hearing with HEW Wednesday or wait until we can get the adequate representation that we want from them.

I want to thank you very much for your statements and for your attendance. I think that it is a good cross-representation of what is going on in the field and I think you have adequately presented to us all of the problems.

We are still searching for some answers and you have given us some valuable suggestions for that.

As Senator Church said at the outset, we hope, at the conclusion of these hearings, to build a record upon which we can make some very positive and very pointed findings as to what the direction is. It has reached the point that we should not be talking about the problems too much longer; we really ought to be talking about the solutions and whether the solutions are adequate.

With the new administration, it is an opportune time to try to get some direction into the home health care program. We all know that it is an area in which savings can be made for institutionalized care.

We also know that the proper amount of our resources are not going into this area, and that home services can be so much better for older citizens who can avail themselves of a better quality of life for a longer period of time, whether they ever have to be institutionalized or prior to institutionalization. It is something that we have talked about long enough, and we ought to be getting on with seeing that we are providing the kind of resources we need.

So I think your testimony will certainly help us in building that record and I want to thank you very much for your attendance. I now turn it over to the staff.

Mr. ORIOL [presiding]. My name is Bill Oriol. I am the staff director of the Senate Committee on Aging.

I just would like to ask Mr. Liversidge a question. In your statement you indicated support for requiring certificates-of-need for home health agencies. Now suppose that a competing home health care provider were to bring operations into your area and perhaps it would be a for-profit agency which happens to be part of a chain. Suppose, too, that its directors claimed it could provide better services at lower expense precisely because it is part of the chain. Now how would the certificate-of-need that you honestly put into effect be of help to you or your competitor?

Mr. LIVERSIDGE. Well, first of all, in our State, because we have no licensure law, a for-profit agency could do business there. But if we had one, what would probably happen is that initially we would both continue operating. Our cost per visit would most certainly go up because the for-profit organization would most likely be a medicare only, or completely—100 percent—self-pay, covering only those people that would pay the full cost of the visit.

We would lose that portion—the medicare and self-pay—of our current income, so we would have to take the balance of our patients' costs and spread that out over our current administrative costs. Conceivably, we could lower some of our overhead, because we would have a smaller agency, but the net results—

Mr. ORIOL. My question was, Which of the two of you would continue or would both of you continue?

Mr. LIVERSIDGE. We would probably eventually go out of business.

Mr. ORIOL. You would be driven out of business?

Mr. LIVERSIDGE. Yes. We would reach the point that our cost per visit would get so high that it would really be pointless to continue. Unfortunately, if we went out of business, that would mean that the people who would not be served would be those who are not covered by medicare.

Mr. ORIOL. Is this what is happening in Florida?

Mrs. WENNLUND. Yes. Even the public agencies that are tax supported are finding that some institutions are absorbing so much of the tax dollar that they just simply cannot subsidize it any more because it is cutting into other services.

Mr. ORIOL. I would like to ask Ms. Kinoy a question. You briefly described the potential of the home attendant program, despite all of its current problems, and despite all of the work that has to be done now to overcome those problems. You are working 4 days a week and for some months have been working to arrive at that. I would like for

you, if you could, to just tell us a little bit more about the positive possibilities here.

Also, at a time when we are all talking about employment opportunities possibly being supported with public funds, do you see a way to make a reformed home attendant program work in this direction?

“VERY GREAT POSITIVE POTENTIAL”

Ms. KINOY. I very much feel that this is a program that has a very great positive potential. I see it as a program that could function very well through the utilization of either public or voluntary agencies that are now in charge of other types of home care programs. I see that it could certainly be run in terms of the development of new employment programs. It can be an important employment program for both older and younger men and women in the community who can qualify for the standards that are needed for care. The supervising agency must be satisfied that the trainees are qualified as a result of the training program.

I wish to add that I would like eventually to see the home attendant program thought of as part of the continuum of care of the different types of home care that can be provided in a community. There are times when a patient needs very intense care in an acute period of illness. There also are times when there is a gradation in the intensity of care needed on a daily basis; for example, a person who only needs care a few hours a day or a few hours a week.

It seems to me that some place in the middle, between intensive care and minimal care, rests what we now call the home attendant program. This is a program where persons with long-term chronic illnesses are provided a lot of care for many hours of the day.

Mr. ORIOL. I see a resemblance in this to the foster grandparent program, and now the senior companion program, where hours are spent with the person, instead of minutes. In fact, one of the articles which appeared recently in the New York Times about the problem showed that a home attendant who had not received his checks from January through now or a few weeks ago nevertheless stayed with the person because that person needed the help.

So you can have a most warm and friendly relationship.

Ms. KINOY. Yes; you can. On the other hand, the worker has to have funds so that he or she and their families can survive as well. These persons have to be paid and they have to be paid adequately because no matter how warm a heart one may have, it is not a very happy kind of a job spending from 8 to 12 to 24 hours a day with a very, very chronically ill, crotchety old person, and for this I think a person should be remunerated.

I feel that probably one of the things that has to happen, Mr. Oriol, is that we must find ways of coordinating many of the existing programs. For example, perhaps a person who now has a home attendant 12 hours a day would be able to receive less care if he had a meals-on-wheels program, a friendly visitor coming in, et cetera. In that way, we would be able to combine some of the many services that are being developed for that person's care.

Mr. ORIOL. Thank you.

57 PERCENT REHABILITATED

Mrs. Walden, you submitted an annual report¹ for your service to our committee along with your statement, and in that you indicated, if I read it right, that 57 percent of the patients who receive your service are discharged because no further visits are needed—57 percent. Only 5½ percent are discharged because of death. So this would seem to speak highly for the rehabilitation possibilities of home health care. Is that a correct interpretation?

Mrs. WALDEN. I think so, yes. As I said earlier, too, we are also connected with a hospital that has an intensive rehab unit within the institution, so a number of our patients come to us after inpatient rehabilitation, and then we provide the followup home rehabilitation.

Mr. ORIOL. I think that is a very positive side of your program.

Mrs. WALDEN. Thank you.

Mr. ORIOL. By the way, minority professional staff member David Rust, and our professional people, Kathy Deignan and Diana Porter, who have worked on this for so long—if any of you have questions, please join in.

I would like to keep this going until about 1 o'clock, if you don't mind waiting your lunch, because I think there are a few things yet to cover, and I have two general questions I would like to ask at the end.

I would also like to ask Mrs. Wennlund—there was a report asking for standards for public health nursing services and what is called chronic obstructive pulmonary disease. This apparently results from emphysema and chronic bronchitis, and it turns out that this is the seventh leading cause of death in Florida.

Mrs. WENNLUND. Yes; that is right.

Mr. ORIOL. That is often preventable and reversible, but you do need special training and sensitivity. I see a relationship between that and your project L-U-N-G. Could you explain a little bit more about that investment of \$5,000 saving \$50,000 and how the same thing might be done in Florida?

DIVIDENDS FROM PREVENTION

Mr. LIVERSIDGE. Basically, what it amounts to is that we took a look at the hospitalization patterns of the patients we have seen with lung disease. We took a look at their hospitalization for 6 months before we began the project and then we took a look at their hospitalization after we began sending our nurse in to visit them.

In some cases, we saw them almost on a daily basis, particularly the more ill people, but then, gradually, as time went on, we saw them less and less. Based upon our observations before and after, and presuming that they would have continued to be hospitalized at the same rate, the investment in the project of \$5,000 resulted in at least \$50,000 worth of hospitalization saved, probably more. We have not gotten all the statistics together yet, however.

Mr. ORIOL. Would you guess that the same thing would happen in Florida?

¹ Retained in committee files.

Mrs. WENNLUND. I would hope so. As a matter of fact, I had to postpone a meeting with the Florida Lung Association representatives that was supposed to be Friday, but we do have an appointment on June 3 to explore some funding for statewide continuing education programs for public health nurses and other nurses in the community with responsibilities to deliver this kind of care.

We would anticipate the same kind of results. In most people, or many people with COPD, the attack is triggered by anxiety. Our conception is that if patients really know what they have or what triggered their attack, how they can deal with these kinds of stresses, and so on, and have a really good emergency plan, then the incidence of these acute phases will be diminished.

Mr. ORIOL. I would like to ask, Dr. Friess—in the letter you wrote to the committee last year, you described in some detail your problems with medicaid, and medicaid is supposed to reach the low-income persons. You mentioned that persons just above that level are quite often not served by anybody.

Dr. FRIESS. Correct.

Mr. ORIOL. But if not medicaid, what? Do you have any suggestions as to what you might replace medicaid with? Could it be a broader medicare program, national health insurance for all age groups, although you have some reservations about that—but what about medicaid?

Dr. FRIESS. I think that the extension of medicare would best service that particular group, as I mentioned, to cover medication costs, a more liberal attitude toward getting extra help in the home, whether it be a home health aide, attendant, or what have you.

I think rather than creating more and different programs, we ought to try to straighten out the two programs we have now.

Mr. ORIOL. Well, we have more than that.

Dr. FRIESS. Well, medicaid versus medicare.

Mr. ORIOL. I wonder about that, too.

Ms. KINOY. I would like to introduce Miss Cornelia White who is down with us today. She has just finished conducting the monitoring of the procedures whereby those persons who were just above the medicaid level get into the medicaid system, and how this takes place in New York City. We would be pleased to send you a copy of this report because, although it is possible for persons to “spend down” to the medicaid—

Mr. ORIOL. That means go broke.

Ms. KINOY. It is a most complicated system that has to be repeated monthly.

Mr. ORIOL. I am glad you mentioned that. If any of the witnesses feel that they have supplementary material, our hearing record will be open until May 31. We are also writing to all the national organizations which, in any way, are concerned about this issue and inviting them to comment. We have heard from them in the past and we know what their general positions are, but we want their comments on the new issues arising from this hearing and perhaps arising from the HEW reorganization and issues which may arise because of that.

I would like to ask Mrs. Breslow—you didn't get a chance to talk about it today, but one of your new concerns is adult day care. I also see Edith Robins here who has worked with the Public Health Service for a number of years on that and many other subjects.

If Edith has any new information on where we are, in terms of the Federal interest in day care, perhaps she could comment after you talk about your plan.

NO HELP FROM TITLE XX

Mrs. BRESLOW. Well, again we are a small agency with just one particular program in mind. We did investigate the possibilities of title XX for support and found them virtually closed in Maryland because of the limited amount of funds that are available and the fact that public agencies receive most of the title XX money. There are very few funds available for new programs on a purchase-of-service basis.

It is my understanding that many programs that were funded in other ways are now under title XX, which makes the availability of new funds very limited, so we have not been successful in getting title XX. We do have title VII Nutrition now which helps a little with the cost of the day care program but at this point we are really on a fee-for-service basis and with a certain amount of scholarship funds available through private sources. We do not wish to limit our program entirely to older people of means.

It is a great concern of ours, but we decided to go ahead and set up day care in hopes that before long we would be able to develop additional funding to subsidize low-income participants.

Mr. ORIOL. How would your day care mesh or support your apartment living project?

Mrs. BRESLOW. By and large, the residents of our apartments have enough going for them already. They have enough activity and socialization opportunities available to them within that program so that I don't feel they need to participate in the day care program as well.

We do have one woman who could not make it in the group homes, and for a variety of reasons—problems in sharing, basically—but she also was not mobile enough for our apartments. She returned to her family, but now we are able to have her in the day care program.

So in that sense there are some people who can no longer function in our group home program, but may be able to utilize the day care program as another alternative.

Mr. ORIOL. One of my general questions to the whole group—it is sometimes said the more in-home services you have, the less the family is likely to continue to help its parents or grandparents. Other people say that sometimes having that in-home service makes it more possible for the family to fulfill its obligations by giving them some relief from constant giving of care and time.

I wonder how you all feel about that?

Dr. FRIESS. I think both are true. [Laughter.]

Mr. ORIOL. Of course.

Dr. FRIESS. Two sides of the same coin. Some people fall in one category and other people fall in the other category.

IMPORTANCE OF RESPITE CARE

Mr. WENNLUND. I think respite care can be very important to those who give 24-hour care day after day, week after week, and sometimes the caretaker may be well on in their seventies or eighties. I have wit-

nessed this kind of situation. It would help to just have someone come into the home to provide personal care for the patient for a short time or to come in and visit or to do some shopping or to provide meals-on-wheels or anything will provide some relief for this person.

There are many homes today where the children or the spouse would dearly enjoy staying home and taking care of this person. They cannot because their income is needed and there is no way they can stay home and take care of this patient and survive financially. It is also very difficult for them to work all day and then come home and be a full-time caretaker in the evenings.

So there are more problems than answers, I am afraid, in this area.

Mr. ORIOL. Ms. Kinoy, Mrs. Walden—the people who receive your help, do you feel it weakens the family, strengthens it, or both?

Mr. LIVERSIDGE. I think it first depends upon the family. I don't think it is a question of which comes first. I think if you have a family that is willing to spend the time with a loved one in the home, then home health can be a very valuable thing. If the family is unwilling, then you may find that the home health situation and having the patient home may be counterproductive. Maybe the nursing home is the best place in that particular situation.

We do need a family member, or at least a friend, in there periodically to help out.

Mr. ORIOL. Mrs. Walden.

Mrs. WALDEN. I agree, but if the family is not motivated and is not willing to provide the care or, in some cases, if the patient is not able or not willing to learn to provide for himself—I think sometimes in our culture so often there is a role reversal during illness and maybe the person who has been the worker and the bread earner of the family suddenly is ill and the other family members have to assume their care. If the family or patient is not motivated to become rehabilitated and assume their own care needs, have health services cannot benefit.

It is kind of nice to have a family hovering when the worker in the family is suddenly ill, so what is the benefit? I think that we can provide a lot of services and they still need to be coordinated—everything needs to be available—but we cannot insist that the family provide this care in the home. If they choose not to, that is their right.

The patient has the right to be taken care of. If he chooses to become dependent, that is also his right. We can offer help but we cannot make him take the help.

Mr. ORIOL. A quick question to Ms. Kinoy. It has been said that some of the home attendants in New York City are aliens. What kinds of aliens are they?

Ms. KINOY. I'm sorry that we have not done an analysis of who they are as yet. This is something that we have heard and we really are not able to document it and I really can't answer that question precisely.

Mr. ORIOL. Before I forget it, I have asked Mrs. Robins before whether she might want to comment on where we are in terms of Federal concern about adult day care or anything else that she cares to mention. She is a long-time friend of this committee.

**STATEMENT OF EDITH ROBINS, DEPUTY DIRECTOR, DIVISION OF
LONG-TERM CARE, HEALTH RESOURCES ADMINISTRATION, DE-
PARTMENT OF HEALTH, EDUCATION, AND WELFARE**

Mrs. ROBINS. I would be very glad to speak about day care.

I think one of the very important things not recognized by those concerned with day care is that day care is not one kind of care, but rather is several kinds of care directed at several kinds of targeted populations.

For example, the kind of care that is currently covered under title XX, commonly referred to as "psychosocial day care," is for the frail or socially isolated individual who needs more protective and individualized supervision than is available at the senior center. Then, there is the more health oriented kind of day care for the individual who requires health maintenance services. Still another kind of day care involves the provision of intensive health services, and this type of day care is generally needed for a limited, rather than an indefinite, period of time. In all of the programs, transportation, psychosocial activities, and nutrition services are required.

Now, I think there are many questions to be answered. What patient mix is most effective in day care programs? When there is a patient mix, what kind of staffing should be provided? Would such staffing raise the cost too high for those who need less intensive health services? This is just a sampling of the multitude of questions that require answers.

Some ongoing programs expect participants to attend 5 days a week, although the basic need might be for only 2 or 3 days a week. Much basic information about day care is needed. I, personally, feel very strongly that if an individual could benefit from day care, this form of care is even better than home care in some cases, because of the socialization provided through day care.

In 1972, a congressional mandate was issued through section 222 of Public Law 92-603, calling for experiments to be carried out to determine whether medicare benefits could be expanded to pay for day care, and whether day care should be a required, rather than an optional service under medicaid. The Division of Long-Term Care of the Health Resources Administration took the lead of carrying out these demonstrations and a report of the findings should be available later in the year.

A MUSHROOMING OF PROGRAMS

A mushrooming of new programs has taken place during the past year, primarily through support provided from title XX, the social services amendment of the Social Security Act.

The Administration on Aging has been given the congressional mandate as a focal point on day care. The health concerns of day care are the responsibility of the Public Health Service. The Social Security Administration is also interested and involved in day care. Obviously, a fragmenting of responsibility exists at the Federal level. Under the aegis of the Division of Long-Term Care, an invitational conference on day care will be held later in the year to provide an opportunity for researchers, practitioners, and policymakers to work together to develop a research strategy on day care. Hopefully, this will provide a

well-grounded starting off place for a much broader thrust in the development of this relatively new concept of care.

Mr. ORIOL. For the record, would you give your correct title?

Mrs. ROBINS. Edith Robins, Deputy Director, Division of Long-Term Care, Health Resources Administration, HEW.

Mr. ORIOL. I have one more general question.

Several of you have referred to a bias in favor of the institution, and Senator Chiles in his statement made a similar comment. What is the cause of this? Why do we just accept it as one of the truisms? You know, some people say it is as simple as physicians who don't want to run the risk of malpractice and so, therefore, will have all sorts of tests made in the hospital whether he or she has absolute control, but I don't think it is that simple.

It is clearly not that simple. Is it just a habit or a way of thinking that causes this, or is there something more concrete?

Dr. FRIESS, would you like to start us off?

Dr. FRIESS. I think it is a way of thinking. We have just got in that groove and we go on; it seems easier for us. I don't think it is to the patient's advantage.

Mrs. BRESLOW. It is tradition and habit, and it got institutionalized in medicare in 1965 and we started out that way. It is kind of similar to the retirement age being 65, institutionalized by Bismarck, and it has been that way ever since.

So I think that is kind of the same reason that we think in terms of the institution.

Mr. LIVERSIDGE. I think one of the problems is the fact that most of us are nonmanagers of our own health. We give this over to someone else. Our attitude is to let somebody else take care of it. When we reach the point where we do manage our own health a little bit better, I think a noninstitutional orientation will come back.

Mr. ORIOL. It gets back to consumer education of health matters as one element.

HEALTH CARE, NOT MEDICAL CARE

Mrs. WENNLUND. I think that historically we have accepted the physician as the authority in determining if the patient is in need of care or not. In all, health care is frequently called medical care. I believe that is in error; medical care is a part of health care and, consequently, all the other phases of health care should not become contingent upon the diagnosis and medical treatment and, therefore, screen out many elements of care that were needed.

Of course, the hospital providing acute care is the site of the physician; this is their working field.

Mr. ORIOL. Did you want to add anything?

Dr. FRIESS. I just wanted to say that is why I made the point about the patient's own responsibility for his health. I see this very strongly; it is a long educational process and it will take a long time.

Ms. KINOR. It seems to me, as mentioned by many of the persons on the panel, that there is a need for institutions just as there is a need for care in the home. We have to be very selective in terms of the patient's or person's needs concerning when one type of care is most appropriate.

The socialization needs for isolated older persons are very im-

portant. Many of us know that in a home for the aged and in the nursing home, the socialization that takes place is of vast importance. For those persons it might be a better alternative than the most complex and wonderfully organized care in the home.

I think that the first statement made by Mr. Liversidge was extremely important where he stated that care in the home has to be considered first and the hospital or nursing home is the other alternative. That is absolutely correct. Home care has to be considered as an independent type of care just as institutionalization has to be.

Mr. ORIOL. Did you have anything else Mrs. Walden?

Mrs. WALDEN. I am thinking along the same lines, too, but why is it that home care is only 1 percent or so versus 99 percent institutional care in terms of third-party payment? The physician must accept the professional nurse and the therapist as able to extend his services to the patient without his daily contact. We must reverse the thinking of all of us, to realize that the physician is not the only professional who can provide the needed patient care. I think all of us tend to see the physician as the primary "care giver," and the physician, of course, finds the institution very convenient because he can see 20 or 30 patients in an hour or two.

Mr. ORIOL. Doctor.

Dr. FRIESS. I have been so impressed with the program that I was very unhappy when I heard that the funds had been cut back. Teaching medical students and then teaching nurses—I was amazed at the rapidity—they got to the heart of the matter with the patient in many cases much faster than the medical student did. I have asked myself many times the question why this was true. In a way I think somehow nurses still go into the profession because of the humanistic side of it, whereas medical students go in for other reasons.

Mrs. BRESLOW. On the issue of maintaining elderly patients at home, I understand that the medicaid regulations are going to be changed, or have been changed, so that the value of care that is given to a parent in the home must be considered as part of his income.

So that will make many people who are receiving medicaid no longer eligible. At this point, children who now will have to assume more of the medical costs may make the decision to put the parent in a nursing home in order not to have to bear that additional burden. In other words, the new regulations are a further disincentive to keep people at home.

I am not sure that is true, but I have heard that it is, and I am very concerned if that is the case.

Mr. ORIOL. I had the impression that it was not going to be put into effect, but does anyone have anything newer on that? I don't.

We will certainly look into that.

Well, I would like to thank the panel for doing just what we hoped we would do. We have had a private physician, we have had a person from the State agencies, the directors of two home health care agencies, the viewpoint from a city perspective, and what a voluntary agency could do. So we see from what we have heard here today people moving in similar directions taking varying courses.

What we hope to achieve during these hearings, and from the work that has already gone on, is some way of assuring compatibility or taking steps to get rid of some of the problems we now have.

I would also like to thank Mrs. Robins and acknowledge her help not only for this hearing but over the years. She has really helped us understand some of the things that are happening.

Thank you very much.

We will continue tomorrow at 10 a.m. in this room.

[Whereupon, at 1:07 p.m., the hearing recessed, to reconvene at 10 a.m., Tuesday, May 17, 1977.]

APPENDIXES

Appendix 1

LETTER AND STATEMENT SUBMITTED BY SENATOR CHURCH¹

ITEM 1. LETTER AND ENCLOSURE FROM JO ANNA DEMEYER, PROJECT DIRECTOR, AND JANE RUNYAN, PROJECT CODIRECTOR, ST. LUKE'S HOSPITAL, BOISE, IDAHO, TO SENATOR FRANK CHURCH, DATED AUGUST 23, 1976

DEAR SENATOR CHURCH: Because the rising costs of health care continues to be a primary concern in Congress, we want to inform you of a cooperative project in our community that involves these issues. "Co-ordinated Services for Discharge Planning—A Community Model" is concerned with those patients residing in the nursing home who no longer need skilled nursing care and could be supported in more independent living situations. The cost of health care for patients can be significantly reduced if these patients can live in a retirement home or in their own home with support from community resources.

The purpose of the discharge planning project is to demonstrate a centralized, coordinated discharge planning program which can be implemented in other communities where it is not economically feasible for each skilled nursing facility to recruit and employ qualified discharge coordinators. A qualified discharge coordinator is a registered nurse with baccalaureate or masters degree preparation which includes community health nursing preparation.

The objectives of the discharge planning project are:

(1) To develop a model which can be replicated in communities throughout Idaho for a cooperative discharge planning program between an acute care general hospital and the communities' skilled nursing facilities.

(2) To evaluate the patient benefits of the cooperative discharge planning project.

(3) To identify the role of the hospital based community health nurse as the discharge planner in the skilled nursing facilities.

(4) To determine the cost of providing a cooperative discharge planning program so that the service can be offered to the skilled nursing facilities on a contractual or fee-for-service basis.

Until now, our project has been funded as a demonstration project by the Western Interstate Commission for Higher Education. These funds will no longer be available when the grant expires January 1, 1977. In order to continue, the program will have to have financial support from third party payers. This is a problem because the laws regarding third party payment under federal programs are directed toward the traditional forms of health care and there are no allowances for innovative, cost reducing approaches. Third party payers have concentrated on payment where services are provided rather than what services are provided.

The project has shown that the clients who have been discharged from the nursing home and are being maintained at home or in a retirement home have reduced the cost of their health care significantly. One example of this reduction is a handicapped adult who was being maintained in the nursing home at a cost of \$558 a month and is now being maintained at home at a cost of \$368 a month. Some of the services which have been utilized by clients following discharge from the nursing home have been nursing, physical therapy, occupational therapy, home meal delivery, and homemaking.

¹ See p. 1 for Senator Church's comments.

During the eight months the program has been operational, many interesting problems have been encountered. For example, there is a time lapse between payment of care in the nursing home and the payment of a grant-in-aid because of eligibility requirements. This prevents the client with discharge potential from being discharged from the nursing home, and he continues to be a consumer of costly health care. Another example is the handicapped adult who becomes employed and earns "too much money" (approximately \$400 a month for a single person, living alone, no dependents) to be eligible to continue to receive his medical care through Medicaid. This person is then forced to abandon his independent living situation and return to the nursing home in order to receive financial help with medical expenses. Obviously, care in the nursing home is much more costly than the care at home.

In our efforts to contain costs and to provide quality health care, four providers have worked cooperatively to implement this discharge planning project which is an example of what can be done. It also exemplifies some of the problems with the federal system of reimbursement for health care. Our concern is that the quality of care not be sacrificed for cost containment and that any more legislation passed regarding health care be responsive to the needs of the consumer and support payment of services wherever they are provided. Currently it is nearly impossible to obtain reasonable third party payment for health care services provided in other than nursing homes or hospitals.

We would be available as a group or as individuals to discuss this program further with you and to explore some possible changes in the system of reimbursement for health care, which could reduce health care costs significantly.

Sincerely,

JOANNA DEMEYER.
JANE RUNYAN.

[Enclosure.]

COORDINATED SERVICES FOR DISCHARGE PLANNING: A COMMUNITY MODEL

ADVISORY COMMITTEE

- Boise Valley Sunset Home : 3116 Sycamore Drive, Boise, Idaho 83702. Administrator, Mr. LuVerne Browen; director of nursing service, Mrs. Celeste Rush.
Grand Oaks Healthcare : 316 West Washington Street, Boise, Idaho 83702. Administrator, Mr. William Scifres; director of nursing service, Mrs. Judy Pinkston.
St. Luke's Hospital : 130 East Bannock Street, Boise, Idaho 83702. Assistant administrator/director of nursing, Miss JoAnna DeMeyer; discharge coordinator, Mrs. Jane Runyan.
Treasure Valley Manor : 909 Reserve Street, Boise, Idaho 83702. Administrator, Mrs. Jean Heazle; director of nursing service, Mrs. Marge Strader.

ITEM 2. STATEMENT PRESENTED BY LARRY M. BELMONT, DIRECTOR, HOME HEALTH SERVICES OF THE PANHANDLE HEALTH DISTRICT, COEUR D'ALENE, IDAHO, BEFORE THE SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE OF THE HOUSE SELECT COMMITTEE ON AGING, FEBRUARY 24, 1976

My name is Larry M. Belmont. I am director of the Panhandle Health District in North Idaho. I am also chairman of the Legislative Committee of the Idaho Association of Home Health Agencies. I am here today as a member of the Legislative Committee of the National Association of Home Health Agencies.

The Panhandle Health District comprises the five northern counties of Idaho, bounded on the north by Canada, on the west by Washington, and on the east by Montana, and covers 7,662 square miles of very beautiful country, roughly equal to that of the State of New Jersey and considerably larger than the combined areas of Connecticut and Rhode Island. The population of the Panhandle Health District is 92,000 at the latest census, or a population density of 12.3 persons per square mile. This population has been known to double during peak periods of the recreational season.

The Idaho Panhandle is economically associated with Spokane, Washington, the hub of the Inland Empire. Our primary industries are lumber manufacturing, nonferrous metal mining and smelting, agriculture and recreation-tourism. Idaho produces half of the silver mined in the United States and the three largest

silver mines in the country are located in Shoshone County, a part of the Panhandle Health District.

In July, 1971, the State of Idaho developed seven health districts, which provide health services to all 44 counties. Until that time, only half of the State received public health services.

The structure of the Idaho health districts is a clear manifestation of what Alfred P. Sloan considered "decentralization with coordinated control." For example, the District Board of Health is appointed by the County Commissioners, and the chairmen of the five Boards of County Commissioners make up the Budget Committee that approves the budget of the health districts. The State of Idaho matches 67% of the money which the County Commissioners give to the Health Districts. In addition, the Health Districts are free to negotiate contracts for other services and to obtain federal and private grants where available. This somewhat complex financial arrangement allows considerable flexibility for the Health Districts in that we are not tied to any single source of financing.

Idaho Code requires that Health Districts enforce all state laws, rules and regulations, but this does not preclude us from passing our own rules and regulations. For example, the Panhandle District has its own environmental health code which is extremely important in protecting the 1,200 miles of lake and river shoreline in North Idaho.

Early in our development we refined our role as that of a local health department. We then set for ourselves the goal to "improve the level of health for all citizens of the Panhandle Health District and we move toward this goal through a process of community education and community organization which will enable us to provide our services in a manner that is available, accessible and acceptable to all citizens of North Idaho." We then established certain objectives that guide us through the year, such as: to educate citizens about health and health service, to develop and expand the planning capacity of the health district by assessing our health and environmental needs of the population, and to help citizens identify and utilize appropriate health resources, etc. This is compatible with C. E. A. Winslow's 1920 definition of public health as "the science and art of preventing disease, prolonging life, and promoting health and efficiency through organized community effort."

Thus, our goal statement indicates that public health is considerably more than Elizabethan poor law. We go far beyond providing services to just the medically indigent or the disadvantaged, for our community health services are available to all citizens.

The Health Districts are primarily concerned, then, with two basic elements of services: environmental health services and personal health services. Concerning environmental health, we are involved with solid waste collection and disposal systems for the five northern counties of Idaho including restaurant inspections and a waste water management study for the Rathdrum Prairie Aquifer. With regard to personal health services, we have been involved in various health services from tuberculosis clinics and immunization clinics to well child clinics, family planning, health fairs and home health. It is important to realize that environmental health ties closely to personal health as we have found out in the lead poisoning situation in Kellogg, Idaho.

I am here today to talk with you about home health which is a basic element of our public health program.

Home health is many things, but to a rural public health department such as ours, home health is both an acute and long-term system of care. It extends the physician, the nurse, the para-professional and other health service capabilities into the homes of isolated patients who would not otherwise be served. Home care, then, is the mechanism by which we extend a coordinated system of medical care into both the homes of isolated rural communities and sophisticated metropolitan centers. But we must also consider home care as an important liaison mechanism of public health, for it reaches not only patients isolated 30-40 miles from our office, but it requires us to relate to other agencies that also serve our patients.

Indeed, an efficiently and effectively functioning home health agency is within itself a manifestation of a true system of health care delivery. It has interrelated functioning objectives and parameters such as relationships to hospitals, speech therapists, physical therapists, nurses, home health aides, nursing homes, druggists and orthotists. A system such as home health provides services which are tied together. The boundary of this system can be defined and controlled by its administrative process; thus, home health becomes an element that pulls together the many fragmented services that are available in our total medical care concept in this country.

To do this effectively the home health agency must be licensed and accredited by meeting the required Federal standards. The role of government in home care at the state, local and federal levels, however, must go beyond simple licensure and accreditation of the home health agency. Medicare licensure and standards should be the basic requirements for all elements of public and private home health agencies receiving any federal funds. If Congress allows D.H.E.W. to vary certain home health standards for certain home health agencies, then it creates a sense of direction that only fragments the total medical care system. This would destroy the present effectiveness of home care which is a coordinating system designed to provide more than simply one service. Therefore, the role of government—state, local and federal—must also be involved in establishing processes which help to coalesce and coordinate all elements of health care that relate to home health.

The future role of home health agencies is vital to any improvement of home care in this country. At this time, there is much discussion of national health insurance, but this has the following problems: quality control, cost control, financing and administration. A careful analyst, however, can find these four elements functioning in any well-run home health agency:

First, there is need for quality control. Proven quality control standards for home health are functioning quite well. The medical societies, hospitals, nursing associations and the various other medical elements have standards for home care. Medicare requires utilization review and also intermediary review of claims for service by each home health agency. The total medical care system may someday meet these kinds of standards and quality control process.

Second, national health insurance must develop a cost control mechanism. In home health the vast array of medical services is already tied to cost control mechanisms as required by Medicare. We are audited each year by an intermediary before final settlement is made and each claim is reviewed before payment. This is in addition to the fact that home care must remain financially competitive with other health services within the market place.

Third, national health insurance will require a financing mechanism. Financing of national health insurance should come from several sources as does home health coverage. Remember that home health financing is coordinated at the local level. For example, most home health agencies seek several sources of funds, not just Medicare or Medicaid financing; they receive public money, private payments and charitable contributions. This requires good management; but too, it requires the home care agencies to broaden their horizons of service so as to not be tied to any single source of income. This gives the agency flexibility which most economists advocate in today's uncertain economic and political environment.

Fourth, there must be an administrative mechanism by which national health insurance can be implemented and managed at the national and local level. Home care agencies have done this with their own boards who are legally and morally responsible at the local level as well as the national via Medicare standards and state licensure requirements. This type of home health administration process ties together all key concerns of Congress as it coordinates varied health services, checks on quality control, and is at all times cost-control conscious. In reading Alfred P. Sloan's book "My Years at General Motors," one can find that the home health administrative concept is analogous to his strategy of "decentralization with coordinated control." The standard decentralization is found in each certified home health agency and the coordinated control comes from the standards set at the national level by Congress. It would not be unreasonable to apply this concept to future health care programs.

Home care is not a single panacea for our total medical care system; however, it is an important element that must be maintained and analyzed carefully in the next few years, for it serves as an interesting model for the implementation of any national health insurance program or other innovative health care programs which most likely will be administered at local and regional levels as is home health.

Home care to us, then, is not a new and exciting concept that is suddenly thrust upon the scene; it is simply a basic element of our total public health program. Home health services have only been paid for by Medicare since 1966. Indeed, Congress, via Medicare, has provided some strong direction for our home care program by moving us from 1,000 visits in 1966 to over 8,000 visits in 1969. Due to the stringent rules placed upon us in 1971, our program dropped below 4,000 visits per year. However, we now are clearly on an uptrend and hope that this movement continues its forward thrust.

As the director of a viable rural public health program, I see many programs initiated at the congressional level. However, they come to us from an array of federal bureaucracies that are sometimes overwhelming and totally confusing to those of us at the bottom of the barrel looking upward. I am convinced that the primary elements of program coordination must take place at the local level. Congress cannot be expected to control all programs at the federal level nor can Congress be expected to interrelate to all problems that we must deal with on a day-to-day basis. With that in mind, we need to strengthen the administrative structure of public health agencies and home health agencies at the local level. To do this, we must begin to think of home health as a broader concept than a single service duplicating approach, for in reality home care is a coordinated system of services.

Congress can get a bigger bang for its dollar by avoiding fragmentation of the home health concept and simply build upon the present medical care delivery system functioning in a home health agency. One way to do this is to consider home health as a system of medical care which can tie together many fragmented services for home care patients.

For example, some literature indicates that nutritional programs will be an important addition to home care in the future. Nutrition, then, at the local level could be coordinated along functional lines by home health agencies and public health agencies. We could pull the W.I.C. grant from the Department of Agriculture and the nutritional program of Title VII of the Older Americans Act into our agency under one administrative heading for nutrition. This would cut down on the administrative overhead now shared because of a splitting of these two separated services in two different local agencies.

Also, we are now bringing into one agency, via the home care administrative process, our home health aides and the homemaker services of the State Department of Health and Welfare. By pulling these together we will provide better professional supervision, eliminate present interagency overlap and provide more comprehensive services to patients. Obviously this will also cut down on administrative costs such as administrative staff, overhead and space.

It is interesting to note that many health agencies, particularly home health, are in the process of strengthening their inpatient education, patient counseling and patient screening services. Thus, it could be said that the concept of home care is leading in an attempt to help patients assume a greater responsibility for their own health care as propounded by Representative Dan Rostenkowski and others.

Patient educational programs could lower their dependence on the total health care system which in turn can lower cost. This is important because careful analysis will show that home care builds upon the patient education which requires the patient to help himself to whatever degree possible.

Congress has developed programs such as the Early Periodic Screening, Diagnosis and Treatment program to screen welfare recipients from the ages 0 to 20. That same screening concept could be applied to home health because the necessary administrative structure and mechanism is available in certified home health agencies. For example, in some of the more isolated communities of North Idaho we have conducted health fairs which are simply a giant home health visit. We have delivered several of our services that are available to our home health patients in these isolated communities that do not have physicians. This mechanism of outreach, contacting people and helping people in their own environment has been greatly appreciated.

From the Attachments A, B, C and D one can see that many of our personal health services are related to home care but are not chargeable to Title XVIII nor Title XIX. This kind of administrative and organizational concept gives a better home care quality of service and there are many experts to draw from within that agency. For example, oftentimes our environmentalists go along with the nurse to assess the environmental conditions in some patients' homes or apartment houses. Other times environmentalists must visit the patient with the public health nurse due to septic tank problems, water quality problems and nuisance abatement problems. By tying these related services together, we can cut down the overhead and still provide better services to patients.

Attachments E, F and G show that home health can be supported by many sources of revenue. This is important because Congress could get a good return on its public service dollar by investing future dollars in better coordination of existing health delivery services. Obviously an excellent mechanism to coordinate these existing services is through a certified home health agency. In this way Con-

gress not only strengthens the local level but it can cut some administrative overhead and provide a more comprehensive service to patients through home health.

Public policy from Congress must dictate better coordination and implementation of services as manifested in a functioning home health agency. This type of congressional leadership means less fragmentation than found in a single service entity.

In summary, home care is a unique process. It is within itself a contained and functional system of medical care within our present fragmented duplicative and sometimes competitive medical care system. A comprehensive home care program ties together the governmental process as well as the private proprietary processes involved in all levels of our present system.

Home care has a tested and ongoing process of quality control, cost control, financing and available administrative process. This conceptual operation at the local level could be destroyed by a policy of allowing single service agencies to fragment the present coordinated home care process. Congress must establish a public policy that will strengthen the present comprehensive program at the local level by looking at home care as an interesting model to be used in implementing its future policy for health. Congress can accomplish this strategy by broadening the present Medicare coverage to other age groups who could benefit from home health service.

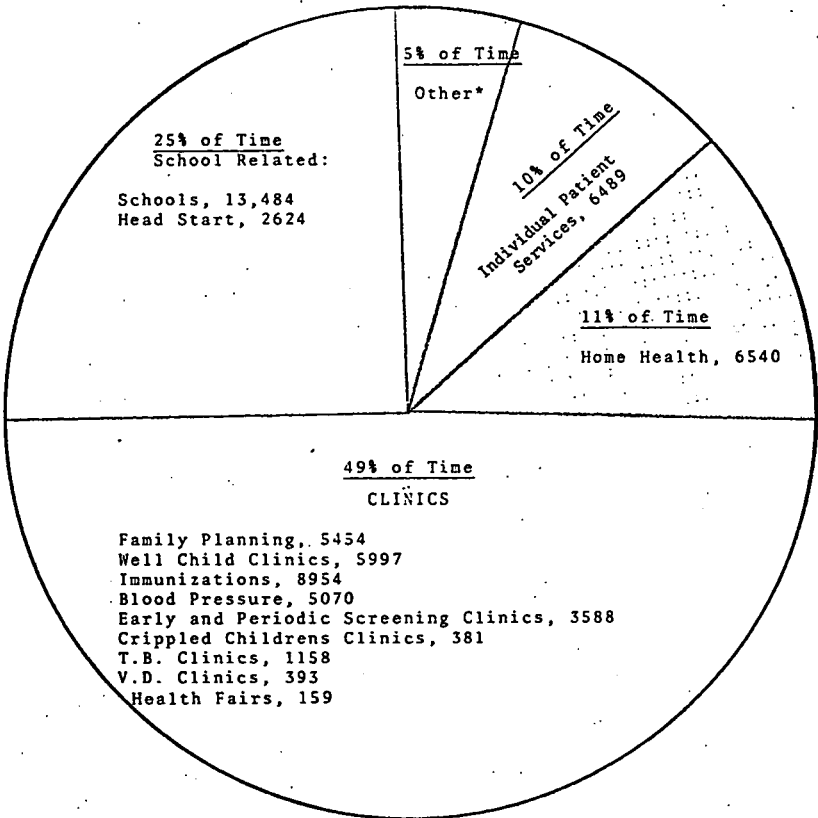
Attachment A.—Panhandle health district I, physical health activities by program, fiscal year 1975

Program :	<i>No. of activities</i>
Home health.....	6,540
Other individual patient services.....	6,489
Family planning.....	5,454
Schools.....	13,484
Headstart.....	2,624
Well child clinic.....	5,997
Immunizations.....	8,954
Blood pressure.....	5,070
Early periodic screening, diagnosis, and treatment.....	3,588
Crippled children's service.....	381
Tuberculosis.....	1,158
Venereal disease.....	393
Classes and talks.....	2,049
Lead study.....	1,047
Health fair.....	159
Total	63,387

PHYSICAL HEALTH ACTIVITIES BY PROGRAM

Total Number of Activities

63,387



(*Other:
Lead Study, 1047
Classes & Talks, 2049)

Attachment C
Fiscal Year 1975

PANHANDLE HEALTH DISTRICT I

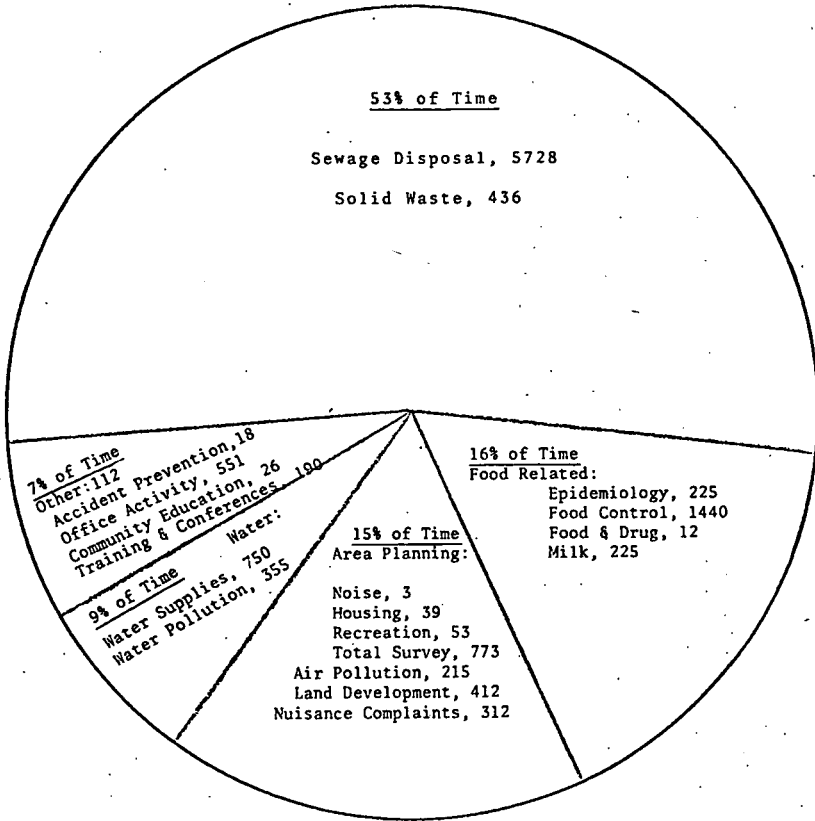
Environmental Health Activities By Program

<u>PROGRAM</u>	<u># OF ACTIVITIES</u>
Water Supplies	750
Sewage Disposal	5,728
Vector	29
Noise	3
Solid Waste	436
Nuisance	312
Housing	39
Air Pollution	215
Water Pollution	355
Radiological Health	7
Recreation	53
Civil Defense	18
Epidemiology	225
Accident Prevention	18
Total Survey	773
Land Development	412
Food Control	1,440
Food & Drug	12
Milk Control	225
Office Activity	551
Community Health Education	26
Staff Training	88
Conferences	102
Other	58
TOTAL	11,875

ENVIRONMENTAL HEALTH ACTIVITIES BY PROGRAM

Total Number of Activities

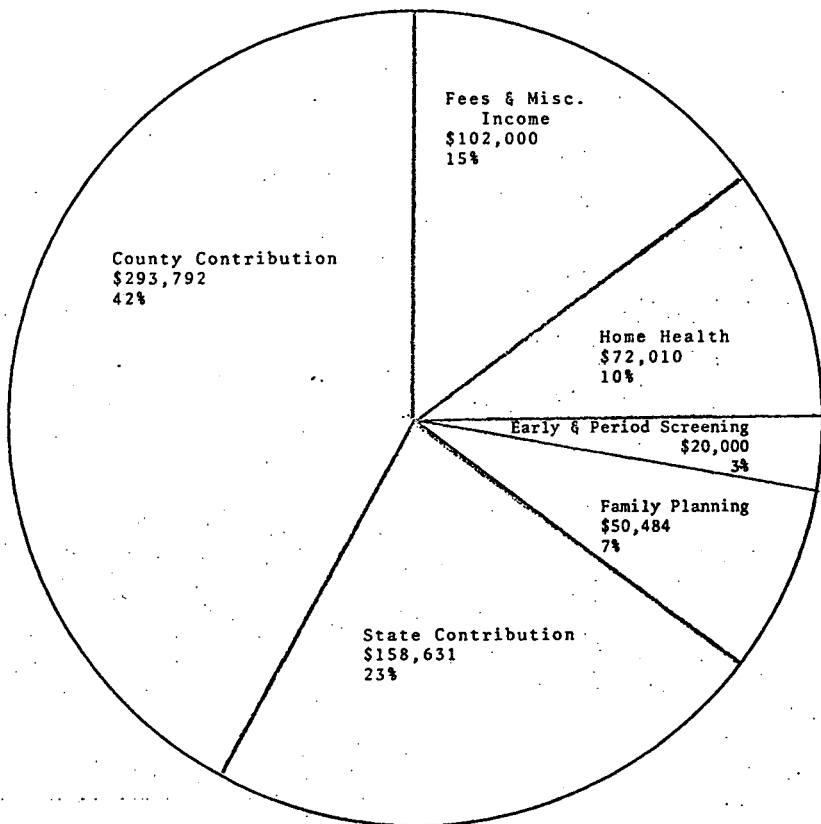
11,875



BUDGET INCOME

Fiscal Year 1975

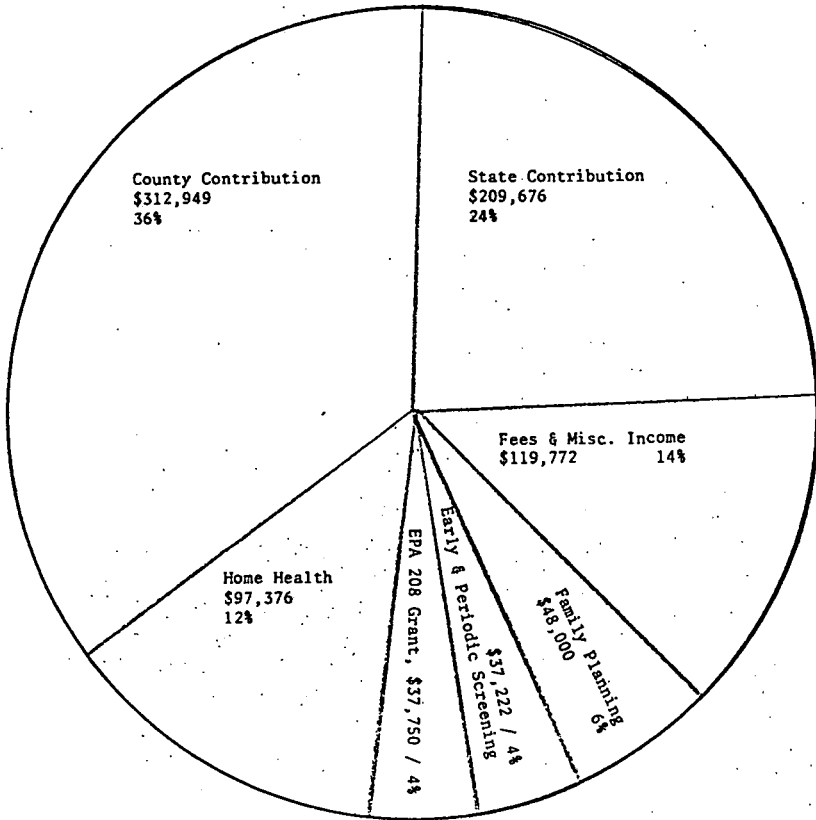
\$696,917



ANTICIPATED BUDGET INCOME

Fiscal Year 1976

\$862,345



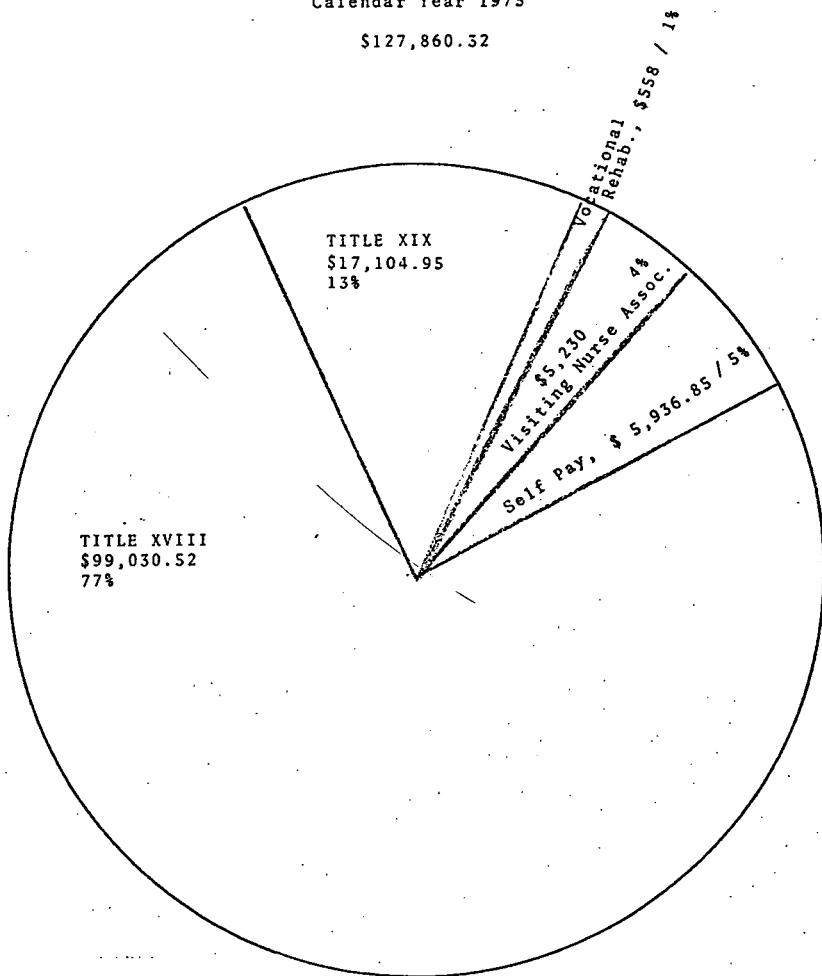
PANHANDLE HEALTH DISTRICT I
COEUR D' ALENE, IDAHO

ATTACHEMENT G

HOME HEALTH INCOME

Calendar Year 1975

\$127,860.32



Appendix 2

ADDITIONAL STATEMENTS AND LETTERS

ITEM 1. LETTER FROM DOLORES M. WENNLUND,¹ R.N., M.S., PUBLIC HEALTH NURSING PROGRAM SUPERVISOR, HEALTH PROGRAM OFFICE, FLORIDA DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES, TALLAHASSEE, FLA., TO SENATOR LAWTON CHILES, DATED MAY 25, 1977

DEAR SENATOR CHILES: Thank you for inviting me to testify before the Special Committee on Aging and for the kindnesses you extended during that hearing. Your consideration is deeply appreciated.

Subsequent to the hearing, the members of the Association of State and Territorial Directors of Nursing (ASTDN) endorsed the recommendations that I made to the Special Committee. Ad hoc committees will be appointed to address the issues of consumer education and professional practice standards of care in specific diagnostic categories.

Other states, particularly Connecticut and Michigan, are facing the same problems in home health services that exist in Florida. The report of the Florida hearings that you conducted are providing insights into the complexity of these problems.

Recent communiques note that the Social Security Administration is planning an experimental program to reimburse non-physician health care providers. This is surely a step in the right direction. However, the reimbursement will be made only to the employer and then only if a physician accepts full legal and ethical responsibility for the services delivered.

These restrictions will limit the extension of services by the independent nurse practitioner. Such a practice would include services to a multitude of patients under the prescriptions of their own personal physicians. Nurses are individually licensed and accountable, carrying their own malpractice insurance. They have every right to expect direct reimbursement as do the dentist, physician, physical therapist, optometrist, social worker and others. It is unfortunate and mistaken to classify the nurse as a "physician extender" simply because there is some overlapping in the services provided. These restrictions will need to be modified if cost effective alternatives to institutionalization are to be found.

Thank you once more for your interest in this vital area of public health care, and for allowing me the opportunity to express my concerns.

If I can be of further assistance, please do not hesitate to call on me.

Sincerely yours,

DOLORES M. WENNLUND.

ITEM 2. LETTER AND ENCLOSURE FROM WILLIAM L. GEE, PRESIDENT, AND MARIE-LOUISE ANSAK, EXECUTIVE DIRECTOR, ON LOK SENIOR HEALTH SERVICES, SAN FRANCISCO, CALIF., TO WILLIAM E. ORIOL, STAFF DIRECTOR, SENATE COMMITTEE ON AGING, DATED FEBRUARY 15, 1977

DEAR MR. ORIOL: On Monday, Mr. Dowd from the Administration on Aging in Washington called me to tell me that Senator Church has requested some information on On Lok Senior Health Services. The Administration on Aging searched its files but could not come up with anything, particularly in relation to our first 3 years of existence as a Day Health Center Research and Demonstration Project under Title IV of the Older Americans Act. We had sent them 30 copies of our full, voluminous report and 50 copies of our executive summary. Under separate cover, we are sending copies of most pertinent material produced by On Lok. We attached some explanatory notes but would be glad to comment further if needed.

¹ See statement, p. 9.

But frankly . . . our cup has runneth over. This only documents what we have been feeling and saying all along about our experience with the Administration on Aging. As taxpayers, we strenuously object and as advocates for the frail elderly we cry out in despair!

On Lok has received a great deal of attention and tax support over the past few years and we have to the best of our ability tried to use the funds judiciously, to document the experience gained, to suggest areas for further development and study and to make recommendations for legislation. It seems that none of this is being analyzed or used by AoA and as fate would want it, we might be out of luck and business because of things like this by June 30, 1977.

We feel that this is particularly deplorable since On Lok seems to have, over the years, developed a community based long-term care program which is very popular with the elderly! It is receiving a great deal of attention—in fact so much so that a local foundation has just given us a grant to assist us in providing more information and education to the many individuals and agencies requesting assistance.

The Committee on Aging of the Assembly of the State of California is introducing legislation on February 24, 1977 which will make Day Health Services a permanent program under Medi-Cal. They are using the experience gained with the Medi-Cal pilot project as a guide.

But with all this, we feel that little has been done by AoA to inform the legislature and public on progress made and urgent legislative developments needed to make this type of care available to the many frail elderly who would prefer it to institutionalization. In fact they have done nothing to assist us in any way with consultations or technical know how on how to go about it to put the program on a permanent funding basis. The most active and valuable assistance we have received from Medicaid and the staff person in charge of day care programs. Over the past two years any monitoring from Washington has consisted of one letter and a short visit by an AoA staff member (not our project officer). It seems unfortunate that not more of this type of responsibility is delegated to the local regional office which certainly could be more helpful at lower cost to the government.

The only material that to our knowledge has been officially used on the On Lok program stems from the Trans Century report. This report was prepared based on material gathered at On Lok in the fall of 1974—about a year and a half after we got started. Unfortunately at that time our recording system was still being developed and I remember on how many "guesstimate" figures I had to give the staff who spent only two days at On Lok.

Our own research and demonstration project report which covers the first three years is still very tentative though certainly much more accurate. It is only now that we can start to give a more comprehensive picture of all the aspects of a program such as On Lok's and start to make predictions on costs and replicability.

Judging from our experience, it takes at least five years to develop and evaluate new services—particularly if one has to start from scratch. More could perhaps be achieved in a shorter time if funding were more adequate and secure and there would be no need to worry about day to day or year to year survival.

We are looking forward to discuss this and more with you during our visit on February 28th at 2 p.m.

Very sincerely yours,

WILLIAM L. GEE.
MARIE-LOUISE ANSAK.

[Enclosure.]

ON LOK DAY HEALTH SERVICES: ITS IMPACT ON THE FRAIL ELDERLY AND THE QUALITY AND COST OF LONG-TERM CARE—A SUMMARY OF FINDINGS

(Prepared by RTZ Associates for the California Department of Health,¹
February 1977)

On Lok Senior Health Services is a community-based day program providing health and health-supportive services to the frail elderly who need these services to remain in the community. Presently On Lok is funded as a MediCal Demonstration Project and as an HEW-AoA Model Project in Aging. This is a sum-

¹Pursuant to Contract #75-53942 with additional research support received through an HEW-AoA Model Project in Aging 90-A-493/02 as part of their evaluation.

mary of a study evaluating On Lok's Day Health Center : its impacts on its participants and on the quality and cost of long-term health care.

Thirty-two recently admitted On Lok Day Health participants were compared to a matched group of 32 elderly persons living outside On Lok's service area. Participants in both groups were assessed by an independent team of health professionals from the California Department of Health in May and November 1976; most (90 percent) kept diaries describing their health services and activities for the five-month interim between assessments.

A number of findings emerged from this study :

(1) A majority of Day Health participants were eligible for institutional care and would have been in a skilled nursing or other protective facility without Day Health services; with Day Health, they were able to remain in the community.

(2) Day Health participants were more frail, with more medical problems than the comparison group and generally lower in mobility and strength; yet they were living more independently and doing more for themselves.

(3) Day Health participants were more socially active, having more trips out and more visits than those in protective environments.

(4) During the study period, 94 percent of the comparison group remained at the same level of care; the remaining 6 percent died. Day Health participants showed more movement: 16 percent deteriorated and 22 percent improved.

(5) Day health participants expressed more satisfaction than the comparison group with the health services they received and with the neighborhood in which they lived. Day Health participants and community residents of the comparison group expressed higher satisfaction in each satisfaction area and with life in general than those in board and care and skilled nursing facilities.

(6) The Day Health group spent significantly fewer days in skilled nursing facilities and yet received more health care, e.g. physician and therapy services, than the comparison group.

(7) Even with adjustments for supplemental income and other governmental programs, the introduction of Day Health did not increase total government costs. Health care expenditures were lower in fact for day health participants. The cost of Day Health services were more than balanced by savings in skilled nursing care. Individual expenditures varied more across Day Health participants and fluctuated more for them over time, reflecting greater program flexibility and a greater likelihood of cost controllability.

CONCLUSIONS

The continuum of services with Day Health was compared to the traditional long-term health care continuum available to the frail elderly. The continuum with Day Health was found to be qualitatively different, providing slightly more medical and significantly more therapeutic services for the same or even slightly lower health care costs. More importantly, Day Health enabled participants to remain in their home communities, to continue their social activities, and to improve or maintain their functional independence. Along with higher expressed satisfaction, these measures indicated the positive impacts of Day Health on the quality of life of its participants, and, in turn, on the quality of long-term health care.

ITEM 3. LETTER AND ENCLOSURES FROM HERBERT SHORE, ED. D., EXECUTIVE VICE PRESIDENT, THE DALLAS (TEX.) HOME FOR JEWISH AGED, TO SENATOR LAWTON CHILES, DATED MAY 29, 1977

DEAR SENATOR CHILES: Thank you for your letter of May 23rd and for your important leadership in the area of the "alternative" issue.

There really are no "alternatives" for the frail, vulnerable and sick aged who require care and services unavailable in their own homes and in the community. The concept of "alternatives" while having a pleasant sound, really is an empty promise, almost a cruel hoax, and has been exploited to justify cost cutting or inaction. Alternatives have generated a great deal of heat, but have produced little light.

I am enclosing a copy of the position statement adopted and endorsed by the National Association of Jewish Homes for Aged in 1974 which I hope you will include in the hearing transcript and proceedings. You will note that what is

called for is commitment and a comprehensive coordinated community program. Pious mouthings won't get the job done. Professional expertise, accountability, adequate funding, and a continuum of services are required.

I am also enclosing a copy of a paper I prepared on "Alternatives" which not only examines the historical role, but poses new approaches and models. I hope you will include this as my testimony.

Once again, I wish to express my appreciation to you and hope you will find this material helpful.

With every good wish, I am

Sincerely,

HERBERT SHORE.

[Enclosures]

The cry for alternatives to institutionalization has become fashionable. Careful examination reveals that parallel services are really not new and have been in existence for a long time. What is new are the possible sources of payment using Medicaid and third party funding. Alternatives can only be as strong as the institutions that sponsor them. They can supplement institutions but will not replace them.

What's New About Alternatives

Herbert Shore, EdD¹

One of my folk heroes is Rabbi David Small, who slept late, went hungry, and stayed home. In the latest Kimmelman book, "Monday the Rabbi Took Off," Small is in Israel, and he finds himself being interrogated by Isk Koshier, the police chief, who says, "Tell me, Rabbi, do you believe in God?" "I suppose as a police officer you would like a yes or no answer. It's a difficult question," the Rabbi went on easily, "since it involves three variables—" "Variables?"

Of course. You ask if I believe in God. Do you mean at this moment in time, or the I of yesterday, or the I of 3 years ago? And what do you mean by "believe?" That's another variable. Do you mean in the same way that I believe that two and two make four? Or the way that I believe that light travels a certain number of miles per second, which I myself have never seen demonstrated but which has been demonstrated by people whose competence and integrity I have been taught to trust? Or do you mean in the sense that I believe that there was a man named Washington who won independence for the American colonies from Britain, or in the sense that I believe there was a man named Moses who did the same thing for the Jews from Egypt? If you think about it, you'll see that there are many more forms of belief, and all of them a little different from each other. And finally, the third variable—God. Do you mean a humanlike figure? Or an ineffable essence? One who is aware of us individually and responsive to our pleas for help? Or one who is so far above us that He can have no interest in us? Or any one of the other conceptions that men have had over the ages? But speaking more generally, I suppose I have the feeling of belief and certainly some times and lack it at others, just as you do, or the Chief Rabbi, or the Pope for that matter.

This lengthy exposition appears appropriate as the subject is nationally approached, "Do you believe in alternatives?" Alternatives in some settings have acquired a God-like quality.

Do we mean at this moment in time? Because for the learned gerontological professionals what are alternatives? The so-called alternatives have been with us for more than a quarter of a century.

And what is meant by alternatives? Is there a real choice between suitable solutions, or are alternatives being suggested which denigrate one service, thus making the so-called better solution more attractive than it really is?

The Recent History of Alternatives

Why the sudden concern and interest in alternatives? Institutional administrators and professionals, who daily work with the aged, recognize there are and will always continue to be, a group of older people who need congregate (institutional) care. The history or evolution of the care home for this group points out that the residents being served are for the most part older, sicker, and poorer than their counterparts who remain in the community.

Parallel services to serve the aged have been developed perhaps not in sufficient number, and certainly not with a sufficient financial support, and will continue to be developed.

There are certain advantages in developing parallel services and certain abuses and limitations. Why then all the furor, excitement, and flag waving? Why are alternatives an idea whose time has come? Can it be that parallel services are indeed the possible proper partial solutions, but for the wrong reasons? Can it be that alternatives are being so highly touted because of the refusal on the part of government to truly face the costs of long-term care? Can it be that the community funding mechanisms have latched on to alternatives because they see a means of redirecting the network of expensive community services, of weakening the appeal and strength of homes for aged and nursing homes? Can it be that the non-profit homes are threatened by discussion of alternatives because they have failed to assume their leadership potentials?

During the campaign and prior to the election of 1968, Richard Nixon told the nation that he had a secret plan to end the war. Unlike Mr.

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Nixon's secret, the Administration came before the White House Conference on Aging with a new and major innovative idea and announcement. The problems of America's aged were to be solved through voluntary efforts, to provide services to older people in their own homes or other places of residence such as group or congregate arrangements like retirement homes, but certainly not the traditional homes for aging or institutions. Institutional care was too costly, psychologically damaging, and a host of scientific data, such as a single study of a Florida Nursing Home, was produced to prove that one-third of the aged in Homes preferred not to be there; thus alternatives to institutionalization was to be the new thrust.

It was demanded of State agency executives on aging that they endorse "alternatives" (which, by the way, they refused to give because the plan, among other reasons, did not provide a sound examination of how alternatives relate to the system—or non-system—for delivery of service to the elderly, or how they would be financed).

One who early recognized the ploy for what it was was Dr. Alvin Goldfarb, who said,

Some persons reason that if you could just keep the elderly at home—as they did in the good old days of big families, big houses and big hearts—there would be no need for nursing homes or other so-called dumping grounds for the aged.

Society tends to censure adults for "neglecting" their parents—indeed, for not reconstructing the preindustrial age "nest" where grandparents could continue to spin tales, help with the chores, amuse grandchildren and live happily (and, of course, healthily) into a poetic demise.

The only trouble with that hypothesis in contemporary life is that it discriminates against those who lack the physical or economic resources to support their parents. And it excludes a lot of others: the aged who have no families, old persons who prefer to live independently and alone, and those who, ultimately, if they live long enough, suffer debilitating mental and physical impairments and need institutional care.

But Goldfarb is more incensed at "myths" about the aged and their callous, uncaring children: "On the contrary," he said, "they (children) tend to maintain them (their parents) at home much past the point when they can give them adequate care." The point, he added, comes when brain damage sets in and the old person becomes "a problem."

We have confused issues of actual physical care and affectionate and protective feeling," he said. "We talk as though the best way to take care of a person in pain is to hug and kiss him rather than to take him to a place (an institution) where he can get the physical and psychological care he needs.

"Extended families," he said, "are a thing of the past" and what is needed is a "revision of our views about family responsibility and family care."

However, "a coordinated approach," the geriatrician said, is obstructed by "an emphasis on do-it-yourself welfare or volunteerism. (Arthur) Flemming (chairman of the 1971 White House Conference on Aging) and President Nixon are saying, 'We don't have to provide old age homes—get the old people to volunteer and do-it-themselves with some nursing care at home and meals on wheels.' But it's at the end—it is beyond the point where self-help aids will be adequate."

"Without social welfare supports to care for the aged," Goldfarb said, "individuals feel angry—with the old for not being independent and self-sufficient, with themselves for not being able easily to integrate caring for them into their life routines, and angry with circumstances when personnel and facilities are inadequate, very expensive or very hard to obtain."

To correct what he termed injustices against both the aged and the middle-aged, Goldfarb called for social intervention by the government as well as a change of attitude toward institutionalization.

Writing in *Medical World News* on "Second Thoughts on the White House Conference," he said,

The first major confirmation of this attitude came at a pre-conference gathering, called on October 22, of delegates from most of the country's voluntary national organizations. At this meeting Dr. Flemming proposed that "action" could be taken on behalf of the aged through such organizations. Flemming's manner in conducting this pre-conference session was an early warning of what was to come. The Administration's plans were signalled when Flemming strongly supported the position that voluntary organizations should be the leaders and carriers of the burden of care for the aged in our society. He pressed for "commitment" to "action." It should be noted that his concept of "action" consisted of holding problem-discussing meetings of national organizations and "community representatives" on a regional level. These would devise and carry through "demonstration projects."

At this preliminary meeting, I pointed out to Dr. Flemming and the participants that effective action required three things: funding, specific implementing legislation, and coordination at the federal level. I also stressed that regional meetings to discover the needs of the aged were unnecessary—because the needs were known. In fact countless effective demonstrations of good delivery of care had been abandoned in the past for lack of funds. Also, the plan was likely to cause bickering and division among interested persons. I suggested that the scheme smacked

of pressing the solutions back to the nonexistent "community" and to private charities, and that in any case it would be so time-consuming as to warrant the designation of "stalling." My opinion about this remains unchanged.

And last, Dr. Goldfarb said, "it would be helpful if the associations would begin to exert pressure on Congress and the Administration to change their minds about the limited value and high expense of services delivered to aged persons who need nursing or related care in the private residence."

When all is said and done *perhaps* alternatives are really an interim issue. As Tobin and others have pointed out, the needs of the aged include money, economic equity, purchasing power, among others. If the older person had sufficient income perhaps he could enter the market place and purchase the services he needs and requires.

Writing in the Winter, 1972, *City Magazine*, Carter McFarland, a former HUD official, says,

But even in the 1930s the wiser heads knew that poor housing is not the sole cause of poverty and slums, and that the provision of good housing will not get rid of the deeper causes of the slum condition. Indeed, bad housing is as much a symptom of slum conditions as it is a cause. Unemployment, poverty, and a lack of marketable skills cannot be solved by housing. Good housing alone will not solve social maladjustments or broken families. Racial discrimination, drug addiction, vandalism, crime, social alienation are problems of human behavior over which the provision of decent housing has little or no influence. They must be solved by education, training, jobs, motivation, social and psychological counseling, and perhaps other remedies as yet undiscovered. Yet, despite all the experience to the contrary, the myth still persists that good housing will eliminate slums.

This quotation points out the possibility of a similar line of faulty reasoning as it relates to long-term care.

In justifying the rush to alternatives, government spokesmen cited an example of the aged who are in nursing homes who would prefer not to be there. They made it appear as though the institution created the abuse rather than the system that failed to develop and provide the continuity of needed services. This technique is one that is commonly used (as it relates to disadvantaged minority groups) and was very carefully examined and analyzed by William Ryan, "Blaming the Victim."

What is meant by "blaming the victim"?

Twenty years ago, Zero Mostel used to impersonate a Dixiecrat senator conducting an investigation on the origins of the Second World War. At the climax of the sketch, the senator boomed out, in an excruciat-

ing mixture of triumph and suspicion, "What was Pearl Harbor doing in the Pacific?"

Twenty years ago, we could laugh at Zero Mostel's caricature. In recent years, however, the victim is being blamed every day in the arena of social problems, public health, anti-poverty programs, and social welfare.

Select Alternatives' Issues, Myths and Problems

What really are the issues, myths, problems with alternatives? Several are examined below:

(1) It has been said that institutions are destructive, lead to depersonalization and dehumanization. Inappropriate use of institutions should be condemned for those able to function or manage in the community with simple support services; they should be able to do so.

But, maintaining some older people in the community for the sake of keeping them in the community is equally destructive and depersonalizing. Some older people have become virtual prisoners in their own homes—skeletons in back bedrooms, out of sight and mind, lonely, isolated, and alienated. The fear of movement in the deteriorating inner city neighborhoods, even if hot meals are delivered, may keep the body alive while the soul perishes. This can be just as much a cruel and unusual punishment as any we have conjured up.

(2) It has been said that non-institutional services are cheaper, thereby implying they are better. This has never been proved. Montefiore Hospital Home Care was just as costly as Institutional Care, for example. Good parallel services are just as costly as institutional, the only saving being in physical plant.

(3) What happens to the older person's rights to "choice" as alternatives are developed?

As the American society becomes more of a cost-conscious computerized actuarialized technology, decisions on where, when, and how people will receive care and treatment will be made on the availability of the cheapest possible resources without regard to the social, emotional, or ethnic religious preferences of older people.

At what point does the older person have a right to determine where he wants to live? The inherent danger in the present system in which *source of payment determines the quality and quantity of care* is that the individual will lose his right to live among his own group when he so wishes.

The alternative proponents lose sight of the fact that even if real alternatives were available in the quality and quantity and range of services

the older person wants and needs—he may still want for social and emotional reasons to live in a congregate arrangement, denominationally sponsored. Homogenization of the aged is not acceptable for a society which prides itself on the importance of the individual. This possibility was previously explored by Elias Cohen in the 1969 American Association of Homes for Aging Proceedings.

Jerome Kaplan's statement on choice is highly relevant.

Immediately prior to the 1971 White House Conference on Aging, national voluntary associations were being requested by the Administration to demonstrate their interest in independent living programs distinct from nursing home care. Nursing home care proponents and care in one's own home proponents matched sharp opinions more than once in committee sessions preparatory to the White House Conference. It is now fashionable—and indeed a major charge to Title III of the Older Americans Act and the approach in the Nutrition law—to seek alternatives to nursing home care. This approach suggests to many Americans at least several possible points: first, there are alternatives; next, nursing home care is the "last stop"; further, independent home care is "better" for the aged American than nursing home care; people prefer to remain in their own homes under all conditions; home care is "cheaper" than nursing home care; and, many people do not have to be in nursing homes.

One of the political attributes of our society is to strive to find a simple solution to a complex, social problem. One of the attributes of the professional is to strive to find a solution to a human problem within his own area of expertise. As the professional operates, he will move in the direction of implementing service based upon his acquired knowledge. But, to what extent does research give us the knowledge indicators, if not answers, to the points suggested above?

The indicators, based on clinical experience, suggest that the word "alternatives" implies there are other answers to the nursing home or institutional care system. It is suggested here, however, that the word "choices" may be more appropriate than "alternatives." Choices indicate an armamentarium of services which will allow for the proper service selection. Alternatives indicate that other service types could replace the nursing home. The aims should be to keep from being underserved, overserved, or misserved, not to give a negative connotation to nursing home or institutional care based on the image of the lowest level of such care offered. Why not the image on the highest level of such care offered?

Or looking at the problem historically:

"In accordance with recent trends, we have long felt that a Home for Aged should admit only persons who, because of illness, personality, or for other special reasons, require that kind of protection." This statement was not written last week or for the White House Conference,

but was from a paper written by Emma Weil Lewi for presentation in March, 1940! This concept is supplemented by a June, 1940, Kate Streng Fox report on Living Arrangements of Aged Clients of a Private Family Agency Boarding Home, the Jewish Social Service Bureau of Chicago.

Or consider the work of William Posner and his Foster Care or Private Residence Program, or Jack Gold's Day Care pilot or Club Residence ideas. The list of pioneer programs is long and impressive. These are reported in a special Bibliography, which appears on pages 34-36 of this issue. So what is new about alternatives?

An answer is found on page 5 of the September-October, 1972, "Aging," which announced "AOA Projects to Test Alternatives to Institutionalization of Aged," and listed the following: Health Care Unit, Simulated Families, Day Hospital, Day Centers, and Health Services. For the first time the federal government was, through a limited number of grants, supporting or paying for the tried and true alternatives professional gerontologists had known about for more than 30 years.

So, what is new is—first, the possibility of payments for parallel services and second, the recognition that isolated, scattered, free-standing, helter-skelter alternatives will not work. A coordinated program of institutional and parallel services—a supermarket of services, is required.

The focus should be not so much on the $\pm 5\%$ of the elderly who currently reside in institutions, but on the 100% of elderly persons, all of whom have certain medical and social needs. The institution should be thought of as one link in the chain of services—not the weakest link, or the sickest, least desirable link, or the final link; simply another link.

The model to care for the needs of the elderly is based on the notion that health care is a right and not a privilege. The health needs of the elderly, as of the population at large, would be met through a variety of services and agencies. National health insurance and/or health maintenance organizations would pay for or provide the basic health services. Hospitals, outpatient services, visiting nurse associations, among others, would offer acute treatment care. A variety of institutions would provide long-term care. Homes for Aging and Nursing Homes would serve the aged chronically ill as would

geriatric hospitals. The difference between the two would be one of degree, not kind.

Social-health needs are met through a range of services. The Home for Aging, nursing home, intermediate care facility, or whatever, is the ideal base of operation, for these are the only facilities with any history of concern for both the social and medical needs of the aged. The panacea model calls for a dramatic increase in the number of affiliated independent-living apartment units with associated medical and nursing services and optional congregate dining facilities. A wheels-to-meals service would be operated in conjunction with each of these communities.

Day centers offering a variety of programs, activities, counseling, and other social services would be available to all older persons. These programs would be coordinated and run in conjunction with existing operations, including homes, convalescent centers, and geriatric hospitals. The institution becomes, in this model, not an alternative or a parallel, but the hub of a coordinated system of services. Familiarity with the circumference and the spokes makes the hub less ominous.

Options should be kept open. An illustration is in order. . . .

What form of transportation is inexpensive, virtually silent, completely pollution free, and has four wheels?

The answer? Two bicycles. Having become sensitive or allergic to alternatives, the author recently read an article on "Alternatives to the Internal Combustion Engine," and the bicycle was not considered an alternative, which is not surprising, considering the relativeness of the word "alternative." Highway Department officials consistently refuse to admit that one alternative to a proposed highway route is no highway at all. There are options—bicycles for one, mass transit for another.

The point here is that in offering the "options" of alternatives, the most obvious have been overlooked.

Putting Parallel Services in Perspective

Jewish Homes for Aging began as shelters for the indigent, those without a family. As the medical revolution progressed, more and more became long-term care skilled nursing and rehabilitation centers. Superb facilities, well equipped and staffed with professionals representing many disciplines were developed.

Some of these Homes developed ancillary and auxiliary services (day care, day center, homemaker, meals-on-wheels), but this usually was done on a piecemeal and spasmodic basis. As Homes recognized they were serving the ill aged, an examination of responsibilities to the well aged and prevention was undertaken. Thus, splendid programs of housing were developed and have proved most successful.

Homes, their professional staffs, and dedicated boards have unquestionably more interest in the aged, more experience, more knowledge and expertise than any other group in the community. Jewish Homes for the Aged and other Homes for Aged of varied auspices must become Centers for the Aged in the community. Some Homes have already accepted the campus concept. The developing program will include

—Housing

Apartments for independent living
Residential homes, retirement hotels, villeges.

—Congregate care

Homes for aged with personal care
Protective environments
Domiciliary, sheltered, custodial care
Intermediate and social care
The skilled nursing facility
Long-term care of the chronically ill and mentally impaired
The extended care facility
Convalescent rehabilitation services
The chronic hospital and geriatric screening and evaluation facility

—Home-based parallel services on outpatient basis

Multipurpose activity day center
Day care
Day care for special groups (handicapped, physically and mentally impaired)
Day hospital
Health maintenance services
Geriatric clinics
Counseling
Wheels-to-Meals
Sheltered workshops
Golden age groups
Information and referral
Pharmacy
Transportation

—Home outreach

Meals-on-Wheels
Homemaker
Home health aides
Foster homes
Telephone reassurance
Protective services
Friendly visiting and shoppers' service
Special service consultations

The combined hardware and personnel of a Home should enable it to develop a total service program so that for every inpatient served, there is one outpatient who comes to the facility and one person served in their own home.

Not only does this maximize the use of existing services, but also it insures the home's monitoring the needs of older people as they change. Homes must assume the leadership for social planning and for serving chronically ill adults and those special groups of aged for whom services are minimal today.

New expanding and innovative services are possible. Where Homes once led, Homes now follow. Homes have become subjugated to allocated funds and unrealistic federal regulations and smoke screens.

Through realistic planning, Homes may be able to do better than provide the kind of

health care and services the nurse criticized so cogently to Will in Aldous Huxley's *Island*:

"So you think our medicine's pretty primitive?"

"That's the wrong word. It isn't primitive. It's 50% terrific and 50% non-existent. Marvelous antibiotics, but absolutely no methods for increasing resistance, so that antibiotics won't be necessary. Fantastic operations—but when it comes to teaching people the way of going through life without having to be chopped up, absolutely nothing. And it's the same all along the line. Alpha plus for patching you up when you've started to fall apart, but Delta Minus for keeping you healthy. Apart from sewage systems and synthetic vitamins, you don't seem to do anything at all about prevention. And yet, you've got a proverb, prevention is better than cure."

An objective which can bring about harmonious relationship between realistic alternatives and sound institutional services is the rational policy for the future.

NATIONAL ASSOCIATION OF JEWISH HOMES FOR THE AGED (NAJHA) POSITION
STATEMENT, 1974

A proposal for the changing concept and role of homes: Extending the "home" as a geriatric agency to a multiservice center sponsoring social and health related programs for Jewish elderly

BACKGROUND TO THE PROBLEM

Jewish Homes for the aged have been the primary and traditional resource for the special elderly population whose social, emotional, medical and nursing needs can best be met in a congregate and therapeutic care environment. Resources for the elderly are scarce and available chiefly through housing and health related governmental programs, and social agency services founded by the community.

Governmental agencies have focused increasing attention on alternatives to institutional care, but funds for alternatives have been meager and program innovations have been limited and not well reported.

Community services for the elderly are frequently uncoordinated. Agencies seek broadbased services to justify increased allocations; hence, in most cases, no one agency has developed a coordinated community approach to deliver geriatric services.

Continuity of services is a much publicized elusive concept which does not lend itself to a "multiplicity of agencies" approach. Comprehensive service delivery systems for the elderly would benefit from a centralized management approach.

OUR POSITION

NAJHA affirms the conviction that older people have the inherent right to alternatives, choices appropriate to their life style and functional capacities; therefore, there is an obligation to assure provision of quality solutions. These rights and needs should give impetus to the fullest exploration and expansion of services and the development of new systems of delivery, staffing and financing. Jewish Homes should become the "center" from which services for the aged emanate. Homes thus become a geriatric agency rather than an institutional service.

This approach is congruent with Marie Callenders concept (in discussing long term care at an AMA conference for medical directors and administrators of long term facilities),¹ "We see as part of an inevitable trend toward a long term care system which will offer a range of services under one central management, ranging from skilled nursing care and intermediate care on an inpatient basis to outpatient day care and home health and homemaker services without moving the patient from one overall management of care to another."

In keeping with our heritage and tradition, Jewish Homes possess the historic commitment, demonstrated managerial leadership and program capabilities, access to resources and public credibility to develop and provide comprehensive, coordinated, community programs, emphasizing the continuity and the breadth of long term care services. Social and health related service systems for the elderly require the resources available in the long term care facilities. Difficulties with alternatives arise when an institution is not recognized as a necessary part of the health service continuum for those who need it.

The umbrella approach of coordinated inpatient, outpatient and outreach services from a central source can help to insure continuity of service, avoidance of duplication and gaps, and provide for efficient operation, since it establishes responsibility and accountability in a single structure.

Jewish Homes providing such leadership will seek the cooperation and mutual participation of other health, welfare, community and governmental agencies to assure provision of service within the total long term care system. Although we believe that the Home is the primary agency to serve as a center for provision of service because of its expertise and commitment, we recognize that other models and patterns may also function, and we welcome that partnership of other agencies which share an interest in the development and delivery of quality services.

OUR COMMITMENT

Within a long term care system, Jewish Homes are committed to serve (from an organized base) these broadly identifiable groups:

(a) Those persons with severe physical and mental disabilities requiring maximum services-total care, who are traditionally served as inpatient;

(b) Those persons with limited intermittent functioning and mobility requiring intermediate and moderate services who may be served as inpatient, outpatient or through outreach services;

(c) Those persons with limited impairments requiring minimal support services who may be served as inpatient, outpatient or through outreach services.

OUR PROPOSAL

The long term care system we propose includes the following array of services: (made available to persons for whom they have assumed care provision and supervision:)

I. Direct Services (to individuals and their families)

A. Resident (Inpatient)

- (1) Skilled Nursing
- (2) Intermediate Care
- (3) Sheltered Personal and/or Domiciliary Care
- (4) Housing with Services
- (5) Night Care
- (6) Special Services for Rehabilitation
- (7) Special Services for Mentally Impaired
- (8) Short Term
 - (a) Geriatric Screening & Evaluation (In conjunction with hospital and clinic resources)
 - (b) Vacation Services
 - (c) Special Services for Convalescing
 - (d) Terminal Care

B. Non-Resident (Outpatient)

- (1) Day (Health) Care Center (Multipurpose, multifunction) for Special and Impaired Groups; Program Includes Counseling, Legal, Pharmacy Services, etc.
- (2) Geriatric Clinics
- (3) Wheels to Meals (on-site feeding)
- (4) Sheltered Workshop (For aged disabled)—work activities center
- (5) Transportation—ambulatory and handicapped
- (6) Crisis Intervention

C. Outreach

- (1) Meals on Wheels
- (2) Chore Services (Homemakers)
- (3) Home Health Care
- (4) Foster Home Care
- (5) Telephone Reassurance
- (6) Protective and Guardianship Services
- (7) Friendly Visiting
- (8) Shoppers Service
- (9) Consultation and Special Services (ADL, Dietary, etc.)
- (10) Information and Referral

II. Indirect Services (To Agencies and Groups)

- A. Planning
- B. Training, Education
- C. Research
- D. Demonstration
- E. Consultation
- F. Innovation of Health Care Models

THE CHALLENGE

The Jewish Homes have a unique opportunity to demonstrate innovation and leadership in the development of a Geriatric service system that combines health care, personal care and social maintenance which can maximize their effectiveness, utilize their special knowledge, reduce inappropriate institutionalization, insure proper utilization of limited resources, lessen duplication of services, and lower costs to provider and consumer.

Homes need to seek new as well as traditional mechanisms for program development and financial operation, such as prepayment, capitation, negotiated

fee, individual and insurance mechanisms. Voluntary Homes must not depend wholly on government for funding programs.

Traditional roles of health care and service delivery, methods of funding, and limited scope of planning and programming, can no longer adequately serve the present populations and future aged. Delivery systems must be enlarged and expanded to include new and innovative approaches of comprehensive inpatient, outpatient and outreach services, under an umbrella of single administration.¹

ITEM 4. LETTER AND ENCLOSURE FROM R. E. ROSENBERG, VICE PRESIDENT, PLANNING AND DEVELOPMENT, HOMEMAKERS HOME AND HEALTH CARE SERVICES, KALAMAZOO, MICH., TO SENATOR FRANK CHURCH, DATED JUNE 15, 1977

DEAR SENATOR CHURCH: In the continuing debate over the exclusion of home health agencies from certificate-of-need (CON) requirements under P.L. 93-641, the health planning law, a new and highly respected academic opinion has been published.

Herbert H. Hyman, Ph.D., Allen D. Spiegel, Ph.D., and Louis R. Gary, in a paper recently published by the Urban Research Center of New York's Hunter College, charge that the certificate-of-need process has not limited costs, as hoped, or has it been an effective way to organize the delivery of health services. For proof, one need only look at the galloping rate of hospital costs and the fragmentation of new and expensive services such as the CAT scanner, the authors point out.

The well known health, urban and social planners and community health professors write that the CON process is biased in favor of institutionally-based providers, and historically, has been used by vested interests to control and maintain their positions within the health delivery system. CON has been deployed to stifle competition, thus effectively quashing innovation, the authors believe.

The Urban Research Center paper categorically states:

"CON should not even be considered until home health care is incorporated into national health planning goals and integrated into state and regional health plans. Such planning must precede CON regulation and it should not be confused with it."

In order to regulate the cost and quality of home health care, the authors advise licensing of agency personnel, utilization review procedures and the institution of standards for provider accreditation, with strict enforcement under national guidelines.

"Without such an approach," the authors say, "the expansion of home health care will be fragmented at a time when the evidence suggests a comprehensive use of home health care is a cost effective alternative for many levels of care given in hospitals and nursing homes."

We hope that you will take a little time to scan the attached copy of the Urban Research Center paper. It's a practical, no-nonsense approach to an issue which, up to this point, has garnered too much emotional rhetoric.

Sincerely,

HOMEMAKERS UPJOHN,
R. E. ROSENBERG.

[Enclosure]

¹ Prepared by the Ad Hoc Committee on Alternatives: Howard Bram, Cleveland; Gerald Cohn, Columbus; Jack Esman, Memphis; Sidney Friedman, San Francisco; Dr. Sol Geld, Clifton; Abe Kostick, Baltimore; Bernard Liebowitz, Philadelphia; Dennis Magid, Bridgeport; Maurice Way, Boston; Al Mendlovitz, Chicago; Dr. Herbert Shore, Dallas; Mel Weisman, Kansas City.

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HOME HEALTH CARE REGULATION: ISSUES AND OPPORTUNITIES

BY

Louis R. Gary
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Allen D. Spiegel, Ph.D.

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SUMMARY

Home health care has historically received a very low priority in the United States. In other developed countries it is a large, integral part of their health care delivery system. Although home health care does not have a strong legislative focus yet, substantial data are helping to build a broad consensus that the vast, unmet need, particularly of the elderly and chronically ill, can best be served by expansion of home health care. In addition, the special needs of children and adults are also receiving attention. There is evidence that chronic diseases have replaced communicable diseases as the major cause of death. The projected growth of the elderly population means that future needs will be even greater. It will not be possible to fulfill these needs in a cost effective way if the institutional bias of delivering services through hospitals and nursing homes continues.

Recent federal legislation has established Certificate of Need (CON) as the process by which health care providers must receive state approval before building or renovating a facility, or adding a new service. Although CON was expected to limit costs, it has not done so. Certainly, strict regulation of cost and quality of home health care is needed, but CON is an ineffective way to organize the delivery of services and limit costs. Furthermore, as a process, CON is biased in favor of

institutionally-based providers and maintenance of the status quo. Vested interests have a history of trying to use earlier state CON regulations to control their turf, limit competition, and consequently stifle innovation. CON SHOULD NOT EVEN BE CONSIDERED UNTIL HOME HEALTH CARE IS INCORPORATED INTO NATIONAL HEALTH PLANNING GOALS AND INTEGRATED INTO STATE AND REGIONAL HEALTH PLANS. Such planning must precede CON regulation and should not be confused with it.

There are alternatives to CON which can achieve quality service and moderate costs, including licensing of personnel, standards for provider accreditation, and utilization review. Planning for these alternatives should begin now. Strict enforcement and national guidelines are essential. Without such an approach, the expansion of home health care will be fragmented at a time when the evidence suggests a comprehensive use of home health care is a cost effective alternative for many levels of care given in hospitals and nursing homes.

Louis R. Gary and Herbert Harvey Hyman, Ph.D., are respectively Visiting Professor of Urban Planning and Associate Professor of Social and Health Planning at Hunter College. Allen D. Spiegel, Ph.D., is Associate Professor of Environmental Medicine and Community Health at Downstate Medical Center, Brooklyn, New York.

RECOMMENDATIONS

The authors believe that the following seven recommendations deserve priority attention.

INCLUDE HOME HEALTH CARE IN NATIONAL HEALTH PRIORITIES

Home health must be included in the priorities being developed by the National Council on Health Planning and Development. Home health agencies should work together to document their position and to present this material for consideration. Health System Plans on a local level should reflect this national priority.

MORATORIUM ON CERTIFICATE OF NEED

There should be a moratorium on the further expansion and inclusion of home health in state certificate-of-need programs.

APPLY LICENSURE REGULATIONS

Using standards agreed to by the national organizations involved in home health, states should be encouraged to license agencies and personnel to perform specific functions and tasks.

EQUITY IN CERTIFICATION

Any home health agency meeting the requirements for certification should be granted certification regardless of funding auspices. There should be equity for all applicants for certification. Periodic recertification of all home health care agencies should be required.

PROMOTE ACCREDITATION AND ENFORCEMENT

A joint committee of representatives from the national organizations involved in home health should develop approved standards, norms and criteria to use in a national accreditation program. Further, this committee should propose enforcement mechanisms in cooperation with government payees, insurers and professional societies, consumers and other associations to legally assure quality care without abuse or exploitation.

COST EFFECTIVENESS

National standards for uniform cost reporting of units of home health service should be developed. This would permit better determination of cost effectiveness of home health and comparison of services and agencies.

INCREASED ACCESS

Medicare's three day prior hospitalization requirement for home health eligibility should be removed. The skilled nursing requirements should be modified to permit other forms of care. Limits on the number of home health visits should be based on medical necessity.

HOME HEALTH CARE REGULATION: ISSUES AND OPPORTUNITIES

Many attempts have been made to contain rapidly escalating costs while assuring an adequate quantity and quality of service. Among these attempts are neighborhood health clinics, prepaid health maintenance organizations, prospective reimbursement, utilization review, and physicians' assistants. Despite these efforts, there was a 20% increase in health costs in 1976, reaching a new high of \$140 billion.

The method that has received wide attention as a possible overall strategy is the certificate of need (CON). Under CON regulations, a health care provider must obtain state approval before a new facility or service can be added. CON has been used largely to make determinations about the largest part of health costs, the supply of hospital and nursing home beds. Many interested parties have called for the application of CON regulations to home health care. The call is being made at the very time that the expansion of home health care is being advocated as a cost saving alternative to institutional care. Not only are institutional providers, hospitals and nursing homes calling for CON regulation of home health care, but so are established, voluntary, not-for-profit home health services.

After reaching a plateau of growth in the first few years after the enactment of medicare and medicaid, there is now a new recognition of the value of home health care and an increase in the number of personnel and new agencies. Some health care professionals are afraid that this rapid increase will bring confusion. Established home health agencies are concerned about uncontrolled growth. They fear its possible harm to the public and to their own reputations. Nevertheless, the federal Certificate of Need regulations issued January 31, 1977, do not include home health care as a service subject to CON review. Individual states may include it in their CON legislation if they wish.

Within this setting, the examination of home health care will cover:

- Special needs of the elderly and other population groups and the future of home health.
- Certificate of Need as a strategy for containing costs and better organizing the health care system.
- Fragmentation and competition among the vested interests for patients and control of home health care.
- Manpower specialization and the need for coordination and continuity of care by licensing and accreditation of personnel and agencies.
- Quality controls and enforcement.
- Cost containment and cost effectiveness.
- Recommendations needed for home health care as an integral part of the health care delivery system.

This examination will support the conclusion that regulation of home health care is absolutely necessary, but Certificate of Need is *not* an effective way to control costs or organize the delivery of home health care.

HISTORICAL OVERVIEW

The home has always been the primary institution for care of the sick. Such care was rendered by family and friends. Reliance on institutional care in hospitals and nursing homes is a 20th century phenomenon as is the professionalization of home health care. During the 15th century, in Ghel, Belgium,

the mentally ill were cared for in foster homes. In the United States, the first organized home care programs was established by the Boston Dispensary in 1796. During the second-half of the 19th century, visiting nurse associations began to develop home care programs. It wasn't until after World War II that the first hospital-based home care program was established at Montefiore hospital in New York City. In 1966, medicare recognized a broader range of services by introducing the term "home health aide."

At the present time, medicare, medicaid, health maintenance organizations (HMOs), neighborhood health centers, older American legislation and social services provisions of the Social Security Act all reflect the growing recognition of the value of home health care services. Abdellah notes that home health was a \$1 billion dollar industry by 1976. Four national organizations have now joined in a definition of home health that shows its wide scope. The National League for Nursing has stated:

The term 'home health care' designates that component of comprehensive health care wherein services are provided to individuals and families in their places of residence for the purpose of promoting, maintaining, or restoring health or minimizing the effects of illness and/or disability. Services appropriate to the needs of the individual patient or family are planned, coordinated, and made available by an agency/institution (or a unit thereof) that is organized for the delivery of health care through the use of employed staff, contractual agreements, or a combination of administrative patterns.

Home health services are provided under a plan that includes, but is not limited to, such appropriate services components as medical care, dental care, nursing care, physical therapy, speech pathology service, occupational therapy, social work, nutrition, homemaker-home health aide services, transportation, laboratory services, and the provision of medical equipment and supplies.

Conditions of payment for home health agencies under medicare requires nursing care plus one other specified service. However, Ryder²³ believes the intent of the law was to provide more comprehensive services. More than 2,000 medicare certified home health agencies were surveyed and 54% were at minimum certification level, 27% had two additional services, and only 4% had five additional services. A 1973 Massachusetts home health survey, reported by Morris and Harris²², showed that 47 agencies said they offered homemaker-home health aide service. In fact, only 14 agencies did so, and that was largely through subcontracting.

Currently, the situation is detailed in Lawson's²⁹ comments about the teaching of chronic illness and aging to medical students and other health professionals. Long term care was inadequate as he noted for the following reasons:

- There was a poor discharge planning by health care institutions.
- Prescribed drug and dietary regimens were incompatible with real life situations.
- There was muddled involvement of professional agencies.
- There was an uncomfortable inference of an absent or remote "leader of the team," the physician.

Addressing the last item mentioned by Lawson, the Massachusetts Department of Public Health³⁰ reported that the most infrequent problem encountered was the failure to

secure physician supervision (only 2% of the survey group). On the other hand, the most frequently encountered problem was that families did not have the commitment or capacity to support relatives in the home (12% of the survey group).

Trager²⁹ summed up the situation by noting that home care provided for the restoration of normal rights and privileges to persons who happen to be ill.

PRESENT AND POTENTIAL HOME HEALTH CARE NEEDS

In considering the needs of the elderly; it is clear that the data solidly support the need for increased home health care. The overwhelming consensus of the 1976 Regional Public Hearings³⁶ on home health care was that many elderly persons were unnecessarily institutionalized. A study of all nursing home residents in Massachusetts by Morris and Harris³² showed that 14% needed *no* institutional care for medical reasons and about 26% needed *little or no* medical care as a reason for institutionalization. Lawson³⁹ also asserts that home health care "is an essential economic and humane component in systematic care of the elderly."

People are living longer and are being afflicted with debilitating, chronic diseases. In 1900 the three leading causes of death in the United States were influenza and pneumonia, tuberculosis and gastritis. Today the leading causes of death are heart disease, cancer and stroke. Influenza is the only communicable disease among the 10 leading causes of death. Two out of every five elderly persons have a minor or major degree of disability and about half of the severely disabled who are elderly have had the disability for five years or more. Furthermore, as Brickner⁷ found, the aged may be home-bound and unable to enter the health care system without assistance. The multiple problems of the elderly may make it difficult for them to get appropriate care.

For long term illnesses such as arthritis, heart conditions, hypertensive diseases and diabetes, the percentage of individuals 65 and over who are disabled by these conditions is almost double in each case compared to the 45-64 age group. The aged population is growing rapidly. Today, there are about 21 million persons over 65 years of age; by 1985 there may be 27 million; and by the year 2,000 there may be close to 31 million elderly—perhaps 17% of the population. There will be more older people with more disabilities needing more health care, more physician visits, more hospital stays, and more personal care.

While it is true that most of the home health care services are needed by the elderly, there is also a home health care need for younger people. A study by the Massachusetts Department of Public Health³⁶ of 3,691 patients served by home health agencies in 1974 showed 77% of the patients were 60+ years of age, and that 4% were under the age of 20. However, a National Health Interview Survey found that 73,000 noninstitutionalized children under 17 years of age had trouble getting around. That survey excluded those with chronic illnesses and impairments. Special aids were needed by another 39,000 in order for them to get around. Assistance from another person was needed by 44,000 more young people, while 37,000 were confined to the home.

Home health care is appropriate from the beginning to the end of life. Yanover¹⁰ compared traditional institutional care and home care for infants and mothers. Patients were discharged as early as 12 hours after delivery with home care follow-up. There were no significant differences in trends or

types of morbidity during the 6-week period after delivery. The home health care given was safe, economically feasible and well accepted by patients. A newspaper³⁷ recently reported that a New Jersey hospital became the first in the state to offer a 24-hour program of home health care to cope with the special needs of terminally ill cancer patients and their families.

Even in situations where most people would think that institutional care would be an absolute necessity, home care is being tested. Mather³⁷ reported on home and hospital care for myocardial infarctions (heart attacks). There was no statistical difference in the mortality rate after 330 days. In fact, the home care group had a mortality rate of 20% compared to the hospital group's 27%. Home care was judged to be a proper form of treatment for many patients, particularly for those over the age of 60 and for those with an uncomplicated attack who were seen first by their family doctors. Haber³⁸ reported similar findings on hospital based home care after a heart attack.

A sampling of the literature of recent years reveals the types of patients and conditions receiving home health care: paraplegics⁴, spinal cord injuries³¹, autistic children³¹, hemophiliacs⁴⁰, strokes³, small bowel resections³², dialysis patients³¹, patients who require oxygen therapy²⁰, handicapped children³¹, dental patients²⁰, retarded children¹⁴, vascular surgery patients⁴, respiratory illnesses³¹, mental illnesses³⁷, terminal illnesses³⁷, young chronically sick⁴⁴, cancer patients³³, patients requiring medication³³, and general early discharges⁴.

In urging home health care at home, Burch³ said, "... the public has the impression that good medical care is only possible in a hospital and that complex diagnostic procedures and measurements and therapeutic measures are always necessary for excellent medical care."

Since statistical data as well as a review of the literature demonstrate that home health care is not confined to the elderly, it is obvious that the expansion of home health services as part of the treatment plan can be applied to a wide range and level of care.

HOME HEALTH NEEDS

The United States has one homemaker for every 5,000 people. By comparison, Sweden has one for every 121 persons, and the United Kingdom has one for every 726 persons³⁴. The National Council for Homemaker-Home Health Aide Services³⁷ projects the need for these services at 300,000 persons, one for every 1,000 Americans under the age of 65 and one for every 100 persons over 65. There will be a problem of qualified manpower if those projections become a national goal. A survey of home health care services received under medicare in 1974 reveals that all 2,222 home health agencies rendered nursing services, 72% delivered physical therapy services, and 67% had home health aide services. In 1974, 57% were government agencies, 24% were visiting nurse organizations, 10% were hospital based, 6% were other agencies including proprietary, and 2% were combined government and voluntary agencies.

The policy problem is how growth should take place. How many agencies are needed? What is the minimum size of an agency, and what services should an agency provide? Should present agencies be encouraged to grow while new operations are kept out? The answers to these questions will shape the type and quality of service available in the decades ahead. We have no national guidelines and little national planning to en-

able the federal, state and regional levels to answer these questions.

On a federal level, Abdellah¹ notes that the Health Services Administration is distributing \$3 million in demonstration grants for expansion and initiation of home health care services for the 600 countries of the country presently without services.

Somers and Bryant²⁹ discussed the need for home care, its neglect, and the advantages to be expected from its use:

- An option for care of the elderly infirm, disabled, and handicapped to receive services while remaining at home.
- Needed assistance to overworked professionals who can supervise care at home with fewer visits to the home.
- Employment for mature persons without much formal education or work experience.
- An opportunity for substantial savings in the fight against inflation.

Target³⁰ also specifies the benefits of home care upon cost and quality:

- Increased range of options for the provider, the community and the individual.
- A selection and combination of services to meet specific needs that is capable of prompt adjustment and of change in kind, intensity and duration of services.
- Services are focused on an individual in need of care

rather than on groups and allows for economy in the use of professional and other staff.

- Makes therapeutic use of the personal environment.
- Well trained paraprofessionals are extensively used.

After 15 years of the study of long-term care and the testimony of hundreds of health consumers and providers, in 1974 the U.S. Senate Sub-committee on Long Term Care³⁰ concluded:

If home health care services are readily available prior to placement in a nursing home, there is convincing evidence to conclude that such care may not only postpone but possibly prevent more costly institutionalization. What is particularly appealing from the standpoint of the elderly is that home health services can enable them to live independently in their own homes, where most of them would prefer to be.

Somers and Bryant²⁹ also echo this comment when they say, "Nevertheless, the broad conclusion is inescapable: home health care, when efficiently organized with good backup services, is a highly cost-effective way of caring for the elderly."

Obviously, the federal priorities for cost control and the surveillance of the quality of care embodied in the National Health Planning and Resources Development Act (P.L. 93-641) and Professional Standards Review Organizations (PSRO) are potential vehicles for providing encouragement and supervision of home health care expansion. Right now, their potential is untapped.

CERTIFICATE OF NEED AND HOME HEALTH CARE

CON: WHAT IS IT?

As of 1976, some 35 states had enacted CON laws, 16 of them mandate coverage of home health care. This is optional since federal guidelines do not mandate its coverage. P.L. 93-641 requires all states to establish a CON program before October, 1980. These programs must have the authority to approve or disapprove "new institutional health services proposed to be offered or developed within the State." Section 1523 of P.L. 93-641³¹ states:

Such programs shall provide for review and determination of need prior to the time such services, facilities and organizations are offered or developed or substantial expenditures are undertaken in preparation for such offering or development, and provide that only those services, facilities, and organizations found to be needed shall be offered or developed in the State.

To carry out these reviews, P.L. 93-641 divided the country into about 200 health service areas, each with a Health Systems Agency (HSA). Within each service area, the HSA must prepare a Health Systems Plan (HSP), a 5 year long range plan for the region, and an Annual Implementation Plan (AIP), a short range plan. The HSP states the HSA goal and objectives and the AIP describes how the HSA intends to work toward the implementation of those goals in the next year.

The HSA reviews CON applications in light of the goals and priorities of its HSP and AIP. Applications related to the HSP's priorities may receive the HSA's recommendation for approval provided other requirements are met. Recommenda-

tions of the HSA are submitted to the State Health Planning and Development Agencies (SAs) created by P.L. 93-641. SAs have final authority in approving or disapproving all CON applications.

To provide a national framework, Congress identified ten priorities in P.L. 93-641 in the formulation of national health planning goals to guide SAs and HSAs. Among these priorities, those that have direct or indirect reference to the home health care are:

- Provision of a plan of primary care for underserved populations.
- Increased use of physicians' assistants.
- Provision of varying levels of care on a geographically integrated basis.
- Concern for quality control and uniform cost accounting.

A National Council on Health Planning and Development will be giving close attention to these goals and others relating to the health needs of the nation. However, the informal interpretation given by government officials to guidelines issued by the federal Bureau of Health Planning and Resources Development was that the HSAs concentrate on acute and long term institutional care in their first HSPs and AIPs.

The failure of P.L. 93-641 to mention the explicit needs of home health care together with the exclusion from coverage by the newly issued federal regulations will further discourage HSAs from emphasizing home health care in their plans. Rationales for home health care's exclusion from the regula-

tions include the fact that such care represents only 1% of the total expenditures for health. However, there is no indication that federal authorities have a desire to prematurely restrict the growth of home health care, even if they have not adopted a policy to encourage its expansion. Still another reason for exclusion is that many of the home health care services and facilities are so small that several would not be eligible for review under the minimal federal Certificate of Need criteria. These criteria require CON review of applications if one of the following four elements is present:

- A new facility or organization is constructed or formed to provide home health care services.
- A capital expenditure in excess of \$150,000 is required.
- There is a specified increase in the bed capacity of the health facility.
- The addition of new health services, except home health services, which were not offered in the preceding 12 months is subject to review.

These minimum federal criteria can be made more stringent by states, which has happened in a number of northeastern states. Such misuse of CON by states is at odds with the implicit federal policy not to use CON to prematurely restrict the growth of home health care. Established home health care leaders expressed a strong interest in CON programs because CON aims to:

- Control and limit the rising costs of medical care.
- Prevent duplication in the use of costly technological equipment and other services.
- Reduce waste of scarce resources, including personnel.
- Rationalize the use of existing and proposed medical services in the region.
- Stabilize resources by balancing them against the established need of the region.
- Handle competition among providers in a fair and equitable manner.

However, policy-makers and professional planners examining the state of affairs in home health care could easily come to the conclusion that the CON program might be a major strategy for regulating the potential for turmoil in the field. Established and respected voluntary non-profit and public home health care agencies witnessing the onrush of new competing entries into their domain, particularly the proprietary and new not-for-profit agencies and the "independent" freelancing aides, envision an erosion of their reputations and see the newcomers as having lower standards. Some urban and suburban areas and overpopulated with home health care services while the rural and inner cities have a dearth of such services. Some agencies are under the scrutiny of tough licensing, accrediting, supervision and standards while others do as they please. Naturally, CON regulation is seen as a positive way to bring some order out of this impending chaos before the field is saturated. One must investigate whether reality conforms to the stated intentions of the CON program.

CON IS A MIXED BLESSING

In a recent book on health regulation and certificate of need, Hyman³³ identifies inefficiency and conservatism as two

important shortcomings in the implementation of CON laws, particularly in their impact on cost containment on hospital expansion.

CON REINFORCES INEFFICIENCY: By regulating only new services and facilities, old, inefficient and high cost facilities may be retained. A new facility or service is measured for need against all existing services. Even if the new service can offer higher quality care at lower cost, the new service will be disapproved if the state regulating agency determines that the need is already being met. Home health care has a proliferation of small, specialized agencies: some are licensed and accredited, and others are not. A CON program will do nothing to organize or improve these services. CON can only require that the new agency show how services will be provided to a needy population in an efficient and effective manner. Only on that basis is the applicant supposed to be approved after meeting some other basic criteria. However, approval of a CON proposal does not really seem to depend on whether a need exists for the service. A recent national study⁴² revealed that almost half of the jurisdictions surveyed approved 90% of the CON proposals even though regional plans for the area showed there was no need for the facility or service.

CON FAVORS CONSERVATISM: It is no coincidence that major national associations, such as the American Hospital Association, have been the chief supporters of CON programs. Between 1964 and the passing of P.L. 93-641 in January 1975, about 26 states passed CON laws. In this interim period, prior to P.L. 93-641, the state decision-making bodies were composed of a majority of health care providers and tended to make decisions in closed or executive sessions.

On the surface, P.L. 93-641 has made the decision-making process more open and democratic. HSA's governing bodies and review committees must have a majority of consumers³³. Nevertheless, the major influence among the various interest groups involved in the review process continues to be the providers³³. Providers see regulation, through CON, as a way of maintaining the status quo. CON guarantees their existence, even if they are inefficient. CON gives them an opportunity to legally restrict new entrants or innovations^{37, 42, 43}. Furthermore, among the public, proprietary, and voluntary non-profit sectors in health, the non-profit sector tends to be the most influential partner, mainly because of its public interest image and because it provides most of the nation's basic hospital services. As a result, the proprietary providers with considerably less influence on the CON committees have not fared as well.

A study by Lewin Associates⁴⁴ showed that 16% of all "for-profit" proposals were rejected compared to only 3% of the "non-profit" and 4% of the "public" CON requests. Similarly, there does seem to be a movement to "freeze out" the proprietary home health care agencies from inclusion in any CON program that is passed. Recent federal regional public hearings³⁶ showed that, in answer to the question, "Should proprietary agencies participate in federal programs?" over 50% of those responding said, "No." Additionally, 80% of the representatives from the voluntary non-profit sector were in opposition. Significantly, when it came to the question of inclusion of home health care in CON programs, 100% of the voluntary, public, and governmental leaders favored inclusion, while a little over 50% of the proprietaries favored it.

Unfortunately, a battle between the profit and non-profit sectors is possible. A CON review body is not likely to approve a home health care application—even if there is a demonstrated need—when the home health care forces argue publicly over whether a project should be accepted or rejected because of its auspices.

IS CON PREMATURE?

There is no agreement among home health care leaders on a definition of home health care goals, accreditation and fund allocation, even though there are encouraging signs in that direction. Until there is more unity, it will be difficult for home health care to compete effectively for a larger share of federal and state health budgets.

HIGH PRIORITY GOALS OF HSPs

It is a misconception to equate regulation with planning. Planning is essentially a normative, technical, dynamic and cyclical process that involves molding fact, theory, and policies in order to politically influence or bring about a course of action. Regulation is based on legal, routinized, rigid, administrative standards that result in decisions to meet current needs.

Regulation is viewed by federal officials as a means of implementing the goals and priorities of HSPs and AIPs. This requires that the HSP/AIPs should be developed first so the HSA review committees can measure CON as well as all other applications. Federal regulations recognize this difference by specifically stating that CON project reviews are not a required function of HSAs and SAs until their HSPs, AIPs and state plans are publicly approved¹⁹.

Home health care is not even mentioned once in P.L. 93-641. However, while home health care services are given attention in the goals being considered by the National Council on Health Planning and Development, this does not assure that HSAs will give much emphasis to home health care in their first year plans. On the contrary, home health care will probably be given a low status—if any status at all—because the informal interpretation of the federal guidelines places top priority on acute and long-term institutional care.

HOME HEALTH CARE NEED MUST BE PROVED

Home health care agencies, like all other applicants, must prove that a need exists for their proposed services. A CON program is based on the premise that a balance exists between the real needs of specified segments of the population and the availability, affordability, and accessibility of services. Need is usually based on statistical data, which are abundant for institutional services.

However, there is only sketchy and unreliable data for home health care in much the same way as there is for the 80% of the nation's ambulatory care delivered in physicians' offices. An interesting evaluation of the difficulties involved in determining the need for home health care has been made by Trager²⁰. Whether data is collected based on community surveys, on home health care agency records, on the availability

of funding, or on the estimates of experts, any number of biases are built into the unsystematically gathered data, limiting their reliability and validity. Under such circumstances, the review committee must fall back upon its own judgments and prejudices as well as its high priority HSP goals to determine whether or not it should approve or disapprove a home health care project.

FINANCIAL VIABILITY AND SERVICE COORDINATION REQUIRED

Even if the review committee were predisposed to approve such a project, the issues of sufficient funds, to run the program and the necessary cooperative formal agreements with other agencies in the health system would still have to be resolved. In addition, the review committee might well have a bias toward a particular model for delivering services. If the CON proposal were not consistent with bias, it would stand little chance of being approved.

As of 1976, 16 states passed CON legislation which required the review of home health care proposals. About 17 states, including some with CON laws covering home health care, require licensure of individuals or agencies engaged in home health care. However, the majority of states are totally unregulated with respect to home health care, except for the federal regulation of medicare requiring agency certification for reimbursement in home health care activities. Given this diversity in state and federal regulations, home health care has an opportunity to resolve some of its own problems.

At the same time, the experiences of those states with CON programs could be evaluated. As the federal regulations state, the Secretary of HEW is sensitive to the concerns of the home health care proponents of CON and plans to monitor the growth and impact of home health care on the health care system²¹.

CON AND THE LACK OF CRITERIA

Besides these problems, there are difficulties in the interpretation of the criteria to be used for review and approval or disapproval of projects subject to CON regulations. Section 1532 (c) of P.L. 93-641 mandates nine criteria. These criteria are vague and imprecise. To illustrate the potential problems the criteria might present, four will be discussed briefly. Section 1532 (c) states that "criteria required . . . for HSA and SA review shall include consideration of at least the following:"²²

- The relationship of services reviewed to the long-range development plan of the provider.
- The need that the population served or to be served has for such services.
- The availability of less costly, or more effective alternatives.
- The availability of resources including health manpower, management personnel, and funds for capital and operating needs.

These criteria represent minimal federal requirements. Many states will go beyond these by adding other criteria or

defining the criteria more precisely. Each will be discussed in turn.

Criterion: "The relationship of services reviewed to the long-range development plan (if any) of the person providing or proposing such services."

An HSA review committee examines the home health CON application against two plans. The first plan is the long-range plan of the home health agency applicant. The CON proposal must be consistent with the phased development of its own long-range plan. The second plan is the HSP developed by the HSA itself. In most instances, the CON application must relate to one or more of the high priority goals of the HSP. Unless the home health care agency's proposal is consistent with both its own plan and the priorities of the HSA's plan, the chances of approval are slim.

In those states where long-range plans are required for health facilities, as in New York, Massachusetts and New Jersey, this poses a special problem for home health agencies which are small. These agencies have neither the competence, financial capability, nor manpower to develop such a long-range plan. Even larger agencies may lack the planning expertise to develop such plans. In addition to expertise, the home health agency applicant must show knowledge of the goals and priorities noted in the HSP to insure that the applicant's long-range plan fits in with the region's needs. An HSP would tell the home health agency such things as the population needing services, the location of those populations and the type of agency that should provide such services. Without this knowledge of the HSP, the home health agency may find its own plan and CON application in conflict with that of the HSA.

Criterion: "The need that the population served or to be served by such services has for such services."

Definition of need is a difficult, complex, and sometimes unrewarding task. A burden is placed on the home health care applicant to specify the need of the population group it plans to serve. This target population should be similar to one of the high priority groups identified in the HSP. To collect the data required to show how a particular project will serve this population is usually expensive and time consuming. In the end, the small home health agency with marginal income will attempt to prove its case based on limited data, and possible place itself in a position of a contest between its interpretation of need and that of the review committee. Where an HSP places a low priority on home health care and the needs of the population served, the applicant is definitely in a disadvantageous position.

Criterion: "The availability of alternatives, less costly, or more effective methods of providing such services."

This criterion places the burden on the home health care applicant to show that its services are less costly or more effective than those already offered to the target population or those being proposed by other applicants.

Again, most home health care agencies may need outside help to perform acceptable cost-benefit analyses or to employ other management techniques which prove need. For example, the home health care agency may be asked by a review committee to show whether a homemaker supervised by a social worker is more effective than a licensed practical nurse or a registered nurse supervised by a physician. Applicants may have to show whether a specialized, single-service agency such

as one that offers only homemakers or home economists can provide a more effective and less costly service than a comprehensive, multiservice home health care agency. Again, the burden of proof is on the home health care applicant.

Criterion: "... the availability of resources (including health manpower, management personnel, and funds for capital and operating needs) for the provision of such services ..."

Essentially, this criterion puts the onus on the home health care agency to prove it can deliver the services it promises to the target population in the manner outlined in its proposal. At the same time, it requires the applicant to show how staff will be secured. The review committee will want assurance that the proposed staff represents an addition to health resources in the region, rather than a redistribution of existing resources brought about by pirating staff from other agencies in the region.

Equally important, the review committee is interested in the financial capability of the agency to withstand delay in payment, heavy start-up costs, or delinquency in payment by clients or third-party payers. The 1976 Regional Public Hearings⁹⁶ said that unfavorable interpretations by government intermediaries caused many small home health care agencies to have a limited capacity to withstand heavy losses. The review committee must be assured that the applicant has the financial resources to serve the population it has specified is in need.

VESTED INTERESTS COMPETITION, INNOVATION, PLURALISM

"Naming the fox to guard the chicken coop" is a classic theme in the analysis of interest group dominance. Established groups seek to hold on to their turf and deny access to newcomers. Often, groups accuse newcomers of failings in the same terms that were used by those who wanted to regulate the established groups. At some point in group development, the established groups have made sure they were written into the process and have, therefore, captured the agency regulating them^{12, 13, 43, 76, 97}.

In the P.L. 93-641 model of health interest-group bargaining, the definition of providers and consumers as mutually-exclusive groups does not insure that they have mutually incompatible interests to keep them honest, according to Viadeck¹⁰⁸ in his examination of HSAs. Providers and consumers do not form homogeneous or monolithic blocs. Consumers on an HSA Board represent many different constituencies—geographic, economic and ethnic. The same is true of providers. The HSAs do not have two major interest groups. Viadeck sees "no majorities in such a system, only a series of fragmented and largely autonomous minorities," with "very strong norms of reciprocity and log-rolling. I get mine if you get yours ..."¹⁰⁸

The HSA's composition shows a bias in favor of interests committed to institutional care mixed with scattered representation from well established voluntary home health interests such as Visiting Nurse Associations. When such institutional interests are given power under CON to regulate entry into home health care, the results become predictable. Just as hospitals and nursing homes view the expansion of established voluntary home health care agencies as a threat to

their control, the established voluntary home health care agencies in collaboration with the institutional providers and some consumers view the proprietary agencies as competing for clients. Such conservative policies hurt the expansion of home health care by keeping out new providers who would vie for the turf. One of the ways this is accomplished is by restricting the definition of need. At a meeting of the National Association of Home Health Agencies, Milton Gan³⁴ explained how:

Some of the very forces which most directly influence the health care delivery structure have a fundamental conflict of interest with respect to encouraging the growth and expansion of home health services . . . As long as a hospital has empty beds that pose a threat to the economic capability of the hospital, the policymakers of that institution would be derelict in their duties if they encouraged the development of those alternative modes of delivery which could further exacerbate the economic threats to the institutions.

The alliance between established not-for-profit voluntary home health agencies and other elements of HSAs to restrict new home health applicants often takes the form of seeking to keep out proprietary home health agencies. Proprietaries have been introducing management practices which pose a strong economic threat and serious competition to the established agencies. While these practices are not new in the corporate world, they are innovative in the field of home health care. Proprietaries sometimes offer services on a module basis, on a 24-hour basis, on a basis of providing lower cost personnel. By using corporate management practices and taking advantages of economies of scale, proprietaries have been able to reduce overhead costs.

On the other hand, established voluntary home health agencies attack proprietaries as interested in profit, not service. The accusation is made that in order for proprietaries to make a profit, they provide poor supervision, drop patients after their funds are exhausted and give little or no training to their staffs. The established not-for-profit agencies are to be commended for seeking to uphold high standards for themselves and others that would prevent such abuses.

Established not-for-profit agencies use the term, "private, not-for-profit" perjoratively to attack new usually smaller not-for-profits as actually representing a profit motive hidden under a tax exemption. On a case-by-case basis, there may be validity to such charges about proprietaries and new, not-for-profits but the generalization does not hold. It comes down to an attack on the newcomer. The Congressional Budget Office considers the charge and dismisses it with caution:

While there is no evidence that proprietary agencies provide poorer quality services than voluntary agencies, some observers believe that these agencies would maintain a profitable operation by selecting the patients who are least sick and thus require fewer resources. Quality control would be quite important but quality of home care is more difficult to monitor than nursing home care because its delivery is as dispersed as the population receiving it.

One way to achieve equitable treatment among new and established providers, not-for-profits and proprietaries would be subject all home health care providers to a rigorous periodic recertification, perhaps every 5 years.

Organizational cost effectiveness usually does not thrive in a monopoly situation. There are some situations in which

CON might be considered a way of containing costs in home health care. One would be if heavy and inflexible capital expenditures were required, as is often the case in hospitals. Then, limiting competition in an area might be desirable. Other situations might include the possibility of saturating the field, or if unmet needs could be easily satisfied by the modest expansion of present home health providers.

Unless vested interests are held in check, competition will be restricted, the benefits of pluralism will be limited to the older established groups, and innovation may well be squelched.

ALTERNATIVE STRATEGIES TO CON

There are other ways than CON to resolve the organizational difficulties of cost containment, quality control and the delivery system. Certainly, the setting of standards and the licensing of personnel could help to achieve some order and solve some of the battles over turf. Establishing norms, standards and criteria for the control of the quality of care being delivered should provide home health care agencies with goals that can be met by all participants. Cost containment requires many approaches including rate setting, as P.L. 93-641 suggests as a priority. In addition, cost alternatives could experiment with coverage for new skills and certify those services for reimbursement. These alternatives offer opportunities to attempt innovative approaches to meet the needs of the public.

DEVELOP AND LICENSE DIVERSIFIED HEALTH CARE PERSONNEL

Licensure is usually administered by state governments for an individual or organization to practice an occupation or activity. Eligibility requirements establish specific educational attainments and other experience to insure quality and legally protect the public from unlicensed, unqualified practitioners.

Supervision of the home health care team is the physician's responsibility, but others also supervise home health workers, such as nurses, social workers and therapists. Each professional group will have to identify the tasks falling within its jurisdiction and the manner in which the aides will work under their general supervision.

Questions of licensure and standards also have to be answered using the history of other health care workers. This has usually been a state function and will remain so. However, national standards have been adopted by the states; these guidelines are prepared by the professional organizations, or other peer groups.

The physician has moved from doing something to the patient to doing something *with* the patient. The division of labor within the health care industry has multiplied, with many levels of care being given by multiskilled personnel. In 1974, there were 66 nursing home employees for every 100 residents. New professional health workers now include physicians' assistants, nurses aides, and occupational therapy assistants. Nonprofessionals in home health jobs are being subdivided to cover household skills such as cleaning and cooking.

In the 1976 Regional Public Hearings³⁶ the consensus (415

to 0) was on the need to expand services and to have broader coverage of homemaker-home health aide services by all third-party payers. There was also broad agreement on including transportation, home delivered meals, nutrition services and 24-hour coordinated services. Witnesses testified that eligibility should be based on the patient's needs. These needs extend beyond the elderly, including children, the handicapped and the disabled. This broad range of needs will require an equally broad range of training.

Based on her research, Abdellah¹ believes home health care programs have demonstrated the ability to expand the capacity of a delivery system by providing needed care while conserving scarce and costly resources—both institutional and manpower. The National Council for Homemaker-Home Health Aide Services² also makes the point:

Institutional care, which requires that employees be on duty around the clock, cannot easily be varied nor does it allow individuals to do as much for themselves as possible. In-home care, on the other hand, can be custom-fitted to the needs of the individual and the families served, while simultaneously making the most of their strengths. For example, the hours a week of care, the duration of care, and the tasks performed by the homemaker-home health aide can all be fitted to the need and can be changed to meet a changing situation.

With the nation going through a period of high unemployment

Although the tasks related to home health care have been grouped into different categories, a consideration of six types gives an overview of the range and scope of personnel and functions as well as an indication of the possibilities of constantly evolving tasks. None of the list are definitive, only representative.

Professional Functions:	Tasks and skills of the physician, dentist, nurse, social worker, podiatrist, speech therapist, physical therapist, occupational therapist, nutritionist, practical nurse, equipment and supplies.
Home Health Aide/ Homemaker Functions:	
• Health Care	Assist with occupational therapy, speech therapy and other therapeutic measures, exercises, medication giving, rubs, massages, hot packs, foot care.
• Personal Care:	Bathing, dressing, walking, transferring patients, toileting, feeding and shaving.
• Household Tasks:	Cleaning, cooking, laundry, shopping, sewing and mending.
• Leisure Tasks:	Transportation to and from social activities, friendly visiting and any activities that the patient enjoys, such as hobbies.
• Escort Tasks:	Accompany the patient to religious services, to visit the physician and, in general, go with the patient providing all required aid.

In a survey of welfare clients to determine their need for home health aides, Lemon and Welches⁴¹ discovered that 715 out of 821 clients (87%) clearly needed attendant care. Of that group requiring care, 64% needed domestic services and 36% needed home health services. Grant²³ also tells of a successful program of the Washington, D.C. Department of Public Health which concentrated on the recruitment, training and supervision of home health aides. In addition to calling attention to the number of new jobs generated by removing inappropriately institutionalized persons into the community, Morris and Harris²² also raised the issue of training people for those jobs.

ment, the ability to employ people with household skills would be beneficial. Several home health care agencies have already demonstrated their ability by conducting work incentive programs (WIN) to train and employ people on welfare. Community Employment Training Act (CETA) programs also bring new people into home health care. Dr. Philip R. Lee⁴⁰, former federal Assistant Secretary for Health, discussing the removal of barriers to outpatient care, noted: "It is also important to provide payment for nontraditional health workers, such as community health aides who may be able to contribute more to helping patients solve health-related problems than can the highly trained professional."

Home health care programs usually have a physician who takes responsibility for the overall continuity of care for the patient. Chapin¹⁰ lists seven responsibilities of the physician in home care services including supervision of the team of workers, awareness of when to use coordinated home care, referral to services, record keeping and exchanging information with others, consultation when required, discharge of the patient, and adviser to the hospital, medical society and others.

When the tasks involved are categorized under the social model, social workers instead of physicians usually assume the leadership role as in Title XX implementation. Levels of care also determine the skills needed to perform the required tasks. Patients may need intensive care, intermediate care or maintenance care. In each instance, the skills will vary.

Home health care recruitment might start at the professional level where more personnel are needed. It has been suggested that welfare recipients may be a source of potential workers along with the currently unemployed and retired persons, such as policemen, armed forces personnel and other civil servants. One program recruited policemen to work in the health field; others are recruiting former armed forces medical corpsmen to become physicians' assistants.

Once recruited, people have to be trained. The CETA and WIN programs offer training opportunities. Some home health agencies have developed core curriculums for the training of their home health aides and homemakers. Self-

instructional materials have been developed by the armed forces, the Hospital Research and Educational Trust and others that may prove useful in training. With the many types of health workers involved, the problem is to make sure their jobs and training do not overlap with similar or closely-related functions of other workers. Continuing education built around a career ladder to help employees advance to higher skilled and higher paid jobs is an essential part of any plan to expand manpower supply.

QUALITY OF CARE: STANDARDS AND ENFORCEMENT

Along with licensure, accreditation of programs and agencies is another alternative strategy to certificate of need. Salkever and Bice⁷⁷ suggested that more attention to quality care mechanisms should be included along with a critical examination of the need to improve CON. Of course, any quality control effort must also be able to enforce standards to prevent abuse and exploitation.

Accreditation is the process by which a designated organization evaluates and attests that an institution or program of study meets certain standards of administration, physical plant, scope and organization of services, including staffing, records and community relations. Many involved in home health care regard the voluntary joint accreditation program of the National League for Nursing and the American Public Health Association⁶⁴ as representing the optimum standards of quality care.

In early 1977, Home Health Services of Louisiana became the first home health agency accredited under the NLN-APHA standards⁶⁵. If this level of accreditation is established as the norm, the federal government might consider accepting it as certification for reimbursement, just as it does for the standards of the Joint Commission on Accreditation of Hospitals.

Standards have been developed for the homemaker-home health aide by the National Council for Homemaker-Home Health Aide Services, Inc.³⁷, along with supplementary services guidelines⁶¹. These standards are widely accepted.

In addition, the Joint Commission on Accreditation of Hospitals⁶⁶, widely respected for its regulatory activities, has a section of standards for hospital-based home care programs in its accreditation manual. This home care section includes standards for administration, organization, medical staff responsibilities, personnel and qualifications, program review and evaluation, clinical records and community participation.

Witnesses testifying at the five regional public hearings⁶⁸ were united in their call for quality assurance. More than half of the witnesses expressed this concern and identified the following problems:

- Inherent difficulties in assuring the delivery of quality care in the home.
- Variability in quality of care under the differing standards of existing support programs.
- Importance of clearly defined, measurable, and enforceable standards for personnel and institutions.
- Need to protect both the patient receiving services and the public's tax dollars from abuse and exploitation.

Quality assurance in the home is particularly difficult because workers in so many locations cannot be easily supervised. Monitoring of care will, therefore, require costly, on-site observations. Furthermore, since the diseases being treated tend to be chronic, incurable and interrelated, it is difficult to separate them.

Evaluations should reflect the patient's ability to function and meet the activities of daily living. Because of the diseases or conditions involved and the realistic expectation that changes in health status may be slight, evaluation should not concentrate on a narrow definition of health status changes.

Some of the difficulty with quality control activities in home health care programs relates to the concepts of "curing" and "caring." Howell³⁰ equates curing with the technological aspects of health care and caring as more closely related to the art of healing. Measurements of caring usually use the following indicators: satisfaction, the effects on family members, compliance with treatment regimens, and broken appointments. The qualifications of a physician who handles home care patients are succinctly stated by Alex²: "Not only must he be thoroughly qualified professionally, but he must have warmth, understanding, a feeling for people, sensitivity, empathy, and ability to understand chronic illness and its impact upon people and families." He must be able to work with other professional groups. He is practicing "medicine with a heart." Philosophical concerns about caring should be part of the basic and continuing education of health professionals and other health workers.

Physicians and others in positions of making referrals to home health care services must be knowledgeable about those services. Physician referral failure was pointed out by Nash and Arno³³ who noted that 58 out of 100 elderly patients were not referred to home care by physicians. Of those 58 patients, 33 were judged to need home care and 10 others required hospitalization. In non of those 43 patients was an appropriate referral made by a physician. Furthermore, their study of 2,652 referrals in 1974 showed 36% were by friends, family and community agencies, 32% by hospitals, and only 18% by physicians. Nash³⁴ believes that the main problem is to educate physicians. A survey of a local medical society revealed that those physicians who knew about the home care services evaluated them favorably, whether they used them or not.

Quality assurance in home health care could be linked to existing mechanisms for quality control such as Professional Standards Review Organizations, utilization review committees, medical care evaluations and governmental review bodies. PSRO guidelines exist for about 300 diseases and conditions. It may be possible to proceed in a similar fashion in developing baseline norms, standards and criteria for use by home health care agencies. The PSRO model might be adaptable.

A movement in this direction is supported by research studies such as Stone's⁶⁸ that showed the results of health care were not statistically different for a random group of general hospital patients, regardless of whether they were treated in the home or the hospital. Neither diagnosis nor prognosis made a difference in the end results at the level of care tested, and physicians and patients strongly preferred home care. Nielsen⁶⁷ reported that it was statistically significant that fewer patients in his home care group of geriatric patients were

admitted to long-stay institutions. Patients also had fewer days stay in those institutions with no difference in survival rates. Home care patients, particularly those with fractures, arthritis and stroke, had a tendency toward higher levels of contentment. In its review of patients discharged from home health agencies in 1974, the Massachusetts Department of Public Health⁴⁶ showed that 75% of the patients remained at home after care was completed, 19% had to be readmitted to an acute care hospital, and only 2% had to be readmitted to a nursing home.

Many of the factors in current evaluations of health care quality have limited application to home health. As Spiegel and Backhaus⁴⁷ note, most of the norms, standards and criteria do not include measurements that deal with the caring aspects of health care. These types of evaluations would be particularly pertinent for home care patients, since the changes in health status could be minor.

Under the federal government auspices, a series of monographs are being developed that deal with evaluating six identified components of a health care system. These components should apply to the home health care system, for example:

- Is access to services equitable, easy, affordable to all?
- Are services acceptable to groups with varied sociocultural backgrounds?
- Are services available within the geographic community?
- Is continuity of care provided with someone responsible for the patient?
- Is the cost reasonable while still maintaining high quality care?
- Is the quality of care up to standards set by experts?

A commonly used quality measurement topology divides health care into three elements for consideration: structure, process, and outcome. Examples of the components of each are illustrated below:

Structure: Facilities, equipment, staffing patterns and job descriptions, personnel with qualifications and experience requirements, organizational arrangements and financing mechanisms.

Process: Technical competence of the providers judged primarily by peers or by accepted standards of care, patient behavior as it influences care.

Outcome: Changes in health status that are reflected in mortality and morbidity rates, disability limitation, distress and dissatisfaction measures.

A major investigation of quality control is underway to try to find relationships between structure, process and outcome. Some believe outcome may not be affected by structure or process and may depend more upon genetics, for example.

Witnesses appearing at the 1976 Regional Public Hearings⁴⁸ overwhelmingly endorsed the need for increased and improved quality assurance and standards with emphasis upon expanded and coordinated services of high quality in a continuum of comprehensive care.

Protection against abuse and exploitation is directly linked to the enforcement of elements such as licensure, accreditation and standards. Spiegel and Podair⁴⁹ explicitly detail a variety of

monitoring methods, utilization review techniques and medical record auditing activities used in medicaid. A key factor in preventing abuse is the manpower needed to enforce the quality guidelines. In addition, the required legal and political power to carry out rigid enforcement has at times proved problematical. Without enforcement, quality control of home health care will remain in never-never land.

As one focuses on the consumer movement in the health field generally, one advocates that consumers of home health care should play a larger role in determining the quality of care. Van Dyke and Brown⁵⁰ advocated the involvement of patients on a consumer advisory committee of home health care agencies. For consumers of home health care, many of the measurements would necessarily deal with elements that are difficult to evaluate in terms of satisfaction. At times, the satisfactions of professionals are also measured as part of the quality control effort.

Allen³ reported on the sources of dissatisfaction of professionals associated with home health agencies especially factors affecting home care referrals. Dissatisfaction was expressed with the quality of home care, with the lack of feedback about patients, with transportation services, with emergency assistance for patients and with the lack of support from the administration on home care referrals, even though quality was rated high on responses.

COST CONTAINMENT AND COST EFFECTIVENESS

We've hardly scratched the surface as far as exploiting health care at home as a cost-saving device. Home visits directed by a physician/nurse team can save dollars and provide good care in a good setting. What's required is for physicians to support this activity more widely than they do at present.⁶⁹

Home health care can be a cost effective method at many levels of care. Its expansion should be encouraged by larger allocations of federal and state health budgets. There are many illustrations that show home health care has reduced patient need for expensive acute hospital care. The illustrations come from insured home care programs, hospital-based programs, and health maintenance organizations (HMOs). Some 113,000 days were saved by the limited home health care-benefits of New York Blue Cross⁵. Denver Health and Hospitals early discharge program reduced hospital stays by 19.2 days per patient¹⁴; and a Portland HMO home health care program reduced acute hospital stays from an average of 5.4 days to 4.9 days⁵⁰. As for long-term care, the Congressional Budget Office¹³ says: "there is evidence that 20 to 40 percent of the nursing home population could be cared for at less intensive levels were adequate community based care available."

If the presumption can be made that unit costs of home care compared to unit costs of acute care and, often, nursing home care are less expensive, then a number of questions are raised. Why do third-party payers including medicare and medicaid limit home health care use so severely? Why do physicians and hospitals make relatively little provisions for cost saving home health care in treatment plans? Why do private insurers and their premium payers including businesses, unions, local governments and individuals demand so

little home care? Why do HEW planners make so little effort to place home health care higher on the agendas of HSAs?

The response seems to be a fear of the aggregate costs of taking patients away from hospitals and nursing homes, or overutilization of home health care, of expansion of home health care by the addition of more social services to the medical services, and of destructive competition through uncontrolled proliferation of home health care providers. Clarification should tell which fears are groundless and show where and how to be on guard against genuine dangers.

Many see CON as a means of protection against cost increases. All too frequently, CON has been looked upon as though it were a proven method of cost containment that could be applied to home health care. On the contrary, as Salkever and Bice²⁷ have concluded, "While the composition of hospital investment is altered by CON, the total level of investment is not reduced . . . These findings are at variance with the presumption that inflation in the costs of hospital services can be reduced substantially by CON controls on hospital investment."

They have urged rate review and PSROs be considered as potentially more useful for cost containment. At the institutional level, cost containment techniques that appear to work in the short run, involve the crude method of reducing labor costs by attrition or by layoff and government wage and price controls. These are all outside the scope of both CON and HSAs.

Furthermore, CON may be mistakenly thought by some to address cost effectiveness, which it does not. CON is not a monitoring mechanism as rate setting and PSROs are. CON does not explicitly deal with quality and manpower. The concept of cost containment is related, but not identical to cost effectiveness. Only the concept of cost effectiveness goes beyond containment and links cost to the quality of care and the impact on the patient.

Michigan's Office of Services for the Aging³¹ in a report to Governor Millikan has recognized that the types of services available are a major influence on cost. The report contends that in northern states, the reliance is on hospitals and nursing homes—with no evidence of a shift in emphasis to home health care. In contrast, they have found southern states are coping with heavy use of health and social care by the elderly with increased use of in-home, outpatient and community services. The Michigan report contends that this is happening in southern states because, "they can no longer afford the higher cost options and personal choice is predominantly for care in one's own home."

In advocating a substantial increase in home health care, the Michigan report³¹ recounted the institutional dislocation and cost shifts that could follow:

As there is greater reliance upon in-home and community services, there should be a decreased reliance upon institutional services, hospital services in particular. The effect is likely to be a declining hospital population, increased per capita costs for hospital services, and subsequent increases in reimbursement rates. If this issue is not addressed, and alternative care services are developed, it is near certainty that the aggregate costs for health/social care will increase at a greater rate than at present.

The danger is real; however, the burden may be misplaced. Given the documented extraordinary costs of hospitalization

and the generally acknowledged inappropriate placements in hospitals and nursing homes, the burden should be on these institutions to prove that, at the very least, continued institutionalization is an alternative to home health care. The hypothesis could be advanced that one reason for restricting the expansion of home health care is that no way has been found to offset the expenditure by a reduction in spending for often inefficient institutional care. In terms of long-term care, the Congressional Budget Office³² has been blunt: "Public programs disproportionately support nursing home care. Less than 10 percent of public funds are for home based services . . . If all services were readily available, the distribution of the disabled and elderly among levels of care would be quite different from its present distribution. There is a large, unmet demand for sheltered living arrangements, congregate housing, and home health care."

In one of the most methodologically sound studies, Greenberg³⁴ estimated 9% of the 1974 Minnesota nursing home population could be cared for less expensively at home. He found that only at the worst disability level is home care as or more expensive than nursing home care. The Congressional Budget Office³³ has noted the danger of a net cost increase by deinstitutionalizing patients and providing them with home health care without considering restructuring long-term care.

Despite evidence of possible savings from deinstitutionalizing some present nursing home residents, the number of the noninstitutionalized disabled who are bedridden or need personal care assistance is so great that patients removed from nursing homes would be quickly replaced. Moreover, home health services, if not limited to those who had first been institutionalized, would be demanded and needed by so many of the noninstitutionalized disabled that there would be a net increase in expenditures.

The evidence is far stronger on the hospital side that home health care could be used without replacement of patients in hospitals. How hospitals and nursing homes cope with the financial loss of patients will be one factor in assessing the rate of increase in the nation's health care costs.

The total costs of health care will increase in any event as a higher proportion of our population becomes elderly and suffers from chronic disease. However, home health care may be able to slow the rate of increase. A substitution of home health care for hospital and nursing home care would seem to meet patient preferences while lowering cost to third-party payers.

The Michigan report³¹ recognized the need for a definition that can provide a balance and prevent abuse.

Additionally, while the report continually refers to possible cost savings, in no way is it suggested that cost savings automatically occur when lower unit cost services are made available. For example, reimbursing a family \$16 per day to care for a 'mom,' rather than pay \$20 a day to a nursing facility would not save program dollars if nine other families who would care for their 'mom' without reimbursement now apply for and receive membership in the program.

Despite such dangers, many reports come out strongly for home health care, not only as an alternative to acute care, but as an alternative to nursing home care. One strong cost argument in favor of such care compared to nursing home care is stated this way.

Just as significantly when discussing costs, home care can be phased out or lessened for many people over time, while nursing home care usually results in dependency and continual use until death. Thus, even if temporary home health or home service costs are not truly 'cheaper' to the State for the first few days compared to a nursing home, they very likely will be over a longer period.³¹

The favorable comparisons between institutional care and home health care make the further expansion of home health care an important policy direction. Present government policies are restricting that expansion. Medicare requires 3 days of prior hospitalization before granting eligibility for home health care. Medicare Part A also restricts the number of home health visits to 100. While the federal medicaid regulations are on the surface more liberal, these regulations permit states to use medicare eligibility requirements for medicaid, which many have. If government planners are serious about cost effectiveness, they must consider an expanded definition of home health care need that permits greater access and, at the same time, balance it by requiring enforcement to prevent abuse.

A distinction needs to be made between two views of cost effectiveness: cross-institutional comparisons of home health care, usually with a hospital or nursing home (which have just been examined) and comparisons among home health providers (which will be reviewed).

The comparisons of cost effectiveness among home health care providers pose many methodological problems, which make it impossible to draw firm conclusions. One key need is to develop uniform reporting³² of costs and services so that firm conclusions can be drawn. Failure to provide for uniform reporting will further complicate attempts to assess cross-institutional cost effectiveness.

Provider financial reports rarely show what was included or excluded in the cost calculation. It is not possible to tell whether capital costs, professional services applied by another body, such as a public welfare department, or physicians' fees were included. There are also no longitudinal studies that could provide a basis for judgments on the duration of care from year to year. Neither is financial and statistical data linked to the intensity, duration, or complexity of the services rendered.

Meanwhile, rough comparisons are being made between not-for-profit agencies, proprietary ones, and among established and newer not-for-profit agencies. Florida³³ found a wide range of costs and staffing ratios among not-for-profits. It also found that so many not-for-profits had relatives on the board that the recommendation was made to set a limit to two relatives per board. Etzioni³⁴ examined the legally permissible but no less unethical abuses that some established and new not-for-profits in health are able to get away with because of their structure. These small numbers of abuses are tainting the good works of the vast not-for-profit area. On the other hand, there have been findings among proprietary providers that suggest excessive billings to medicare for lavish comforts of the providers. A number of other serious scandals have broken out among proprietary providers. What these findings reveal on the cost issued is that agency auspices is not a useful way of examining cost, and may, in fact, be irrelevant. If any generalizations can be made, it will after more uniform cost reporting.

The expansion of home health care is warranted on cost grounds based on the present federal and state definitions of need. Decision makers considering expanded definitions of need for federal and state reimbursed services will find, as the Congressional Budget Office has, that the area of unmet need is frequently in home health and not in new institutional care.

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Of course, all the views expressed are the authors' responsibility and do not represent a position of Hunter College or its Urban Research Center.

ITEM 5. LETTER AND ENCLOSURES FROM GEORGE L. MADDOX, PH. D., DIRECTOR, CENTER FOR THE STUDY OF AGING AND HUMAN DEVELOPMENT, DURHAM, N.C., TO WILLIAM E. ORIOL, STAFF DIRECTOR, SENATE COMMITTEE ON AGING, DATED MAY 13, 1977

DEAR MR. ORIOL: This letter follows several long conversations between us prompted by the question "whatever happened to alternatives?" Our discussion focused specifically on two recent papers of mine which suggest at least partially why we talk so much about alternative forms of services for older persons and do so little.

First, there is the matter of cost. Such evidence as we have continues to be inconclusive and inadequate to the questions we really must ask and answer. The typical argument about alternatives develops like this.

Some individuals who are currently being institutionalized could be adequately cared for outside institutions. Never mind how many or how confident we are that we can identify these misplaced individuals reliably and validly, we know there are some. And, of course we know, at least intuitively, that non-institutional care must be more economical than institutional care. It follows, therefore, that community-based care, if it were available as an option, would reduce the cost of services for older persons.

This plausible and attractive argument is critically deficient in several ways. Consider two individuals for whom competent clinicians had identified the same impairments, had proposed the same management, and were agreed that the management could be provided in either a long-term care institution or at home by publicly financed, community-based services. Would the cost be the same in both cases? So far as I am aware, we do not have conclusive evidence on this matter but some pilot work at the Duke Center and by our colleagues at the GAO-Cleveland Office suggests that the cost would be the same if the service were provided at public expense. This is counter to the argument of proponents of community-based care who are sure such care is economical.

The apparent contradictions may be resolved if we make one of three assumptions. We may assume that individuals in institutions typically receive more care than they need and community-based care is appropriately reduced. Or assume that community-based care is typically less extensive even if we cannot certify it as appropriately reduced. Or assume that in the community a large part of the appropriate care is shifted from the public to the private sector, specifically to kin or friends. Our experience suggests that all three of these assumptions have some basis in fact and, cumulatively, help explain why community-based care appears to be economical from the standpoint of public cost.

I stress "appears to be" because another element of cost must be considered—i.e., total public cost of care. If community-based care were demonstrated in fact to be a substitute for institutional care or to reduce use of services in a particular population, then we could conclude that community-based care is economical. Unfortunately we do not have convincing evidence for such a conclusion. And every informed discussion of the issue concludes, so far as I am aware, that the presumptive evidence is otherwise: namely, the cost of community-based care will be an "add on" cost, not a substitution. The primary reason for this conclusion leads to a second critical issue—the organization of services.

All observers tend to agree that services in the U.S. generally and services for older people in particular are fragmented and ineffectively coordinated. Each service unit makes its own determination of what it will offer to clients and makes its own determination of cost. Said another way, we do not begin with a fixed amount of resources for services and concern ourselves with the sub-optimal allocation of those resources to achieve a defined desirable outcome. This is the problem to which I allude in my paper presented at the US/UK conference on dependency in late life. The failure to understand that the issue of cost is inevitably related to the issue of the organization of services leads inevitably to inconclusive and unprofitable discussions about the comparative cost of community-based and institutional care. Moreover, preservation of the issue of cost tends to distract us from the key issue, the issue of organization. My third point follows.

Our federal legislation has tended to reinforce the fragmentation of services for older persons and has impeded the development of community-based services as an alternative to institutionalization. My impression—and it is only an impression—is that legislators in fact suspect that community-based care in a non-system of services will constitute an "add on" cost.

If we were to move toward a system of care in which clinically appropriate

alternatives could make a difference, we would have to meet three conditions not currently met.

(1) A procedure for the reliable, valid assessment of functional impairments which could be used for assignment of individuals to appropriate services;

(2) The availability of appropriate services to which to assign impaired individuals; and

(3) Adequate procedures for assessment, assignment, and care.

In the typical community, none of the three conditions is met. As a result, we not only continue to argue interminably about whether alternative care is a feasible as well as an abstractly attractive option but also continue to provide inappropriate, costly and ineffective care to many older persons.

Based on our experience at the Duke Center with our continuing OARS research and the related experience of our GAO colleagues in Cleveland, I am confident that we are conceptualizing and are addressing the issues in a useful way. We can certainly assess impairments of older persons reliably and validly. We know how to describe in useful ways the services which are or might be provided to older persons and how to assess their impact. We have had the opportunity to observe a system of services for older persons in Glasgow, Scotland, which in our estimation is as near to optimal as we can imagine. We feel that some models of an integrated care system are badly needed in the U.S. and is feasible. The creation of such a model depends not on its feasibility but on the intention of the Congress to resolve some unresolved but resolvable issues regarding alternative care.

I very much hope that your hearings will result in a proposal to develop models of comprehensive care which will provide evidence which will inform future discussion and action in behalf of improving services for older people. We would all benefit.

Sincerely yours,

GEORGE L. MADDOX.

[Enclosures]

COMMUNITY AND HOME CARE: THE UNREALIZED POTENTIAL OF AN OLD IDEA

(By George L. Maddox, Duke University)

The human and economic cost of excessive dependence in late life is very high. In both the United States and the United Kingdom we have become increasingly aware of how high that cost is already, and worse, how high it might become. Modern technology has tended to produce affluence, increased life expectancy at birth and, concomitantly, a high proportion of older persons in our populations. Unfortunately, improved life expectancy does not insure freedom from disease, impairment and disability; on the contrary, among adults, the risk of disease, impairment and disability is a function of age (National Center for Health Statistics, 1971; Harris, 1971). Societies that know how to prolong life regretably do not know how to insure personal independence for older persons. This is why we must give serious consideration to minimizing excessive dependence in late life.

Dependency in late life demands attention. The proportion of older persons in the United States and the United Kingdom has more than doubled in this century. Currently, more than 10 percent of the population in the United States are 65 years of age or older: in the United Kingdom the proportion is already over 13 percent. About one third of the older persons in both societies are very old, that is, 75 year of age and over. If a Zero Population Growth rate is achieved and sustained in the two countries, an additional 6 percent might be added to those proportions. The implications of these proportions for health and welfare services are staggering. But we should not dwell on the conjecture of demographers about the future. The aging populations already with us appear to be quite enough for the managers of our social institutions in the foreseeable future. Long average life expectancy, a distinct achievement of modern societies, has proved to be an embarrassment and a current threat to existing institutional arrangements not only for health and welfare but also for income maintenance, transportation, housing, and education. Medical education and health delivery systems in both countries were designed to manage acute, not chronic illness; they are therefore mismatched with the particular needs of older persons for preventive, primary, and long-term care and, one might add, with the general needs of all adults. The mismatch is troublesome in the United Kingdom (Anderson, 1974; Andrews *et al.*, 1971; Harris, 1971; Somers, 1976) and dramatic in the

United States (Glazier, 1973; Garfield *et al.*, 1973). The trouble and the drama flow from statistics on how the health and welfare needs of older persons translate into the utilization of health and welfare resources. Among adults in the two countries, utilization of health and welfare services is a function of age; as a rule of thumb, older adults consume health and welfare services at a rate of about two and a half to three times greater than adults generally.

The threat to established ways of doing things have been perceived most acutely by the managers of health and welfare institutions where the pressure is most immediate. It is small comfort to recognize that those who are responsible for transportation, housing, and education are beginning to share in the general discomfort with institutional arrangements that were not designed with late life in mind. There has been an understandable tendency for all of us who are not yet old to discuss with academic detachment the "problems of the old" or "the old as a social problem." A more accurate assessment is that many if not most of the "problems" we associate with older people may lie in our institutional arrangements, not in older people.

Social systems that are ostensibly designed to help solve our problems sometimes have an oppositive effect. This is well known to social scientists, as indicated in Robert Merton's phrase "the unintended consequences of purposive action" which he used to describe the latent functions of institutional arrangements. Simone de Beauvoir has made the same point about modern, technological societies with great force in "The Coming of Age" (1971, p. 807):

"... Society cares for the individual only insofar as he is productive. The young know this. Their anxiety as they enter in upon social life matches the anguish of the old as they are excluded from it. Between the two ages, the problem lies hidden by routine. . . . Between youth and age there turns the machine, the crusher of men—of men who let themselves be crushed because it never occurs to them that they can escape it. Once we have understood what the state of the aged really is, we cannot satisfy ourselves with calling for a more generous 'old-age policy,' higher pensions, decent housing and organized leisure. It is the whole system that is at issue and our claim cannot be otherwise than radical—change life itself."

Simone de Beauvoir's insight anticipates the basic conclusion of this paper: The substantial potential of community and home care, a type of care which has particular relevance for older persons, will be realized only when such care is an integral part of a comprehensive, coordinated health and welfare delivery system. The necessary integration, I will argue, has in fact been achieved to a substantial degree in the United Kingdom and, for the most part, not at all in the United States. Thereby hangs the tale which will be developed in this paper.

THE ARGUMENT IN BRIEF

My argument is as follows. In the first place, community and home care for older persons are a piece of common sense in response to demonstrably common problems of dependency in late life. Community and home care are old ideas which reflect such obvious good sense that arguments about evidence to document need, feasibility and merits appear to be gratuitous and dilatory. The great majority of the health needs of older persons in both the United Kingdom and the United States are currently met, more or less adequately, in the community and at home. More of these needs can be adequately and economically met there.

Second, the economics of community and home care has continued to be controversial. Intuitively, non-institutional care ought to be cost-effective and there are many who assert that it is. However, this imputed cost-effectiveness has been more convincingly asserted than demonstrated as we will see below, few attempts have been made to demonstrate the cost-effectiveness of community and home care with adequately designed studies in the United States, where there is some compulsion to have research evidence when such matters are under consideration. No such compulsion is in evidence in the United Kingdom, where traditionally there is a preference for reliance on the testimony of experienced practitioners rather more than on the data of social scientists.

Third, in any case, the issue of cost-effectiveness is probably a diversion and not the issue which must be addressed. The fundamental issue appears to be the presence or absence of a comprehensive, integrated system for delivering care to older persons. Whether such a system of care exists determines whether community and health care are cost-effective and, more importantly, whether the substantial potential of community and home care is realized. Each of these points will now be developed.

MORE NON-INSTITUTIONAL CARE OF OLDER PERSONS IS NEEDED, FEASIBLE AND
DESIRABLE

The basic argument for community and home care may be summarized as follows. The social process by which health care is allocated is imprecise. Older persons appear to be particularly vulnerable to binary "all-or-none" responses; they tend to receive too little care or too much. Consider mental health services, for example. Older persons are under-represented in community mental health clinics and over-represented in state mental institutions. The probability of a mismatch has been clinically established and need for a particular type and quantity of service is high (Williams et al., 1973). In systematic assessment of carefully drawn samples of older persons living in the community and in long-term care institutions, using a reliable, valid instrument for evaluating functional status, colleagues at the Duke Center for the Study of Aging and Human Development have found about 12 percent of the individuals surveyed appear to be interchangeable; that is, at least 12 percent of the institutionalized older persons in the study have a demonstrated personal and social resource which is sufficient to sustain them in the community and about an equal percentage of older persons living in the community are so impaired that experienced clinicians would expect them to be institutionalized.

There is an understandable but consequential tendency to equate health care and medical care and to use hospitals extensively in both the United States and the United Kingdom. The first three quarters of this century have been a veritable golden age of scientific medicine. Common infectious diseases have been substantially mastered. Hospitals, which played a relatively minor role in health care at the turn of the century now assume a dominant role in health care. Hospitals, especially teaching hospitals and the medical specialists who control them, now consume more than half of the economic resources allocated to health care in both countries. In the United States the allocation for health care is currently about 8 percent of the Gross National Product and in the United Kingdom, about 5 percent.

Although concern has been expressed in both the United States and the United Kingdom about the total cost of health care, much more concern has been expressed about over-specialization of medical care, maldistribution of services, excessive concentration on in-patient facilities, and neglect of adequate arrangement for long-term care outside of medical facilities (Glazier, 1973; Scientific American, 1973; Maddox, 1971; Shanas and Maddox, 1976). Just how substantial these concerns can be illustrated by a review of the epidemiology of health and of related health care needs among older persons.

Risk of chronic disease, impairment and disability is a well documented function of age among adults (National Center for Health Statistics, 1971; Harris, 1971). In one substantial comparative study which included older persons living in the community in both the United States and the United Kingdom, Ethel Shanas and her colleagues (1968) found very similar patterns of impairment and disability. The United States National Health Survey reports that a large majority of older Americans have at least one identifiable chronic condition; 46 percent of older persons have a chronic condition which limits their normal activity and 36 percent experience some limitation in a major activity. Amelia Harris has documented that 70 percent of the impaired individuals identified in a large national sample in the United Kingdom were 65 years of age or over. She reported impairment rates of 22 percent for persons age 65 to 74 and 38 percent for persons aged 75 and older.

A number of important observations are suggested by this documentation of high levels of impairment and disability among older persons in both countries. On the one hand, we would expect what we in fact observe about the utilization of health care by older persons in both countries; as a rule of thumb, older persons consume most types of health care resources at a rate of about two and one half to three times higher than adults generally. In the United States a distinct health care industry, the nursing home, has been developed primarily to serve disabled older persons. This industry has generated almost 16,000 facilities and 1,175,000 beds and produces 369 million resident days of care at an average monthly cost of \$479 and an annual cost of over \$8 billion (U.S. Vital and Health Statistics, 1975). There is evidence that a substantial number of individuals in long-term care institutions could be appropriately served in the community or at home (Williams, *et al.*, 1973; Controller General of the United States, 1974; Hurtado, *et al.* 1972). The economic cost of unnecessary institutionalization and inappropriately high levels of care are consequential. For the record, we must

stress that the evidence of inappropriate institutionalization must not be interpreted to mean that a majority of institutionalized older persons can be managed appropriately and economically outside special medical facilities. Our experience, at Duke suggests that the typical older person in a long-term care facility has significant functional impairment.

On the other hand, while the demand for health care is high among older persons, it is well below its theoretical maximum. This is so, in part, because morbidity in a population is never translated perfectly into demand for health care services (Maddox, 1972). As cases in point, we should note again here that community surveys of impairment and disability in both the United States and the United Kingdom have identified far more older people who are at risk for seeking health care than in fact do so. In the United States, for example we are impressed—intimidated might be the more accurate word—by the over one million older persons who occupy beds in nursing homes at any point in time. We hear very little, by contrast, about at least an equal number who are receiving care at home, primarily from a household member (Maddox, 1975). And among older persons who are receiving whatever health care they receive at home, about one third require constant care over a long period of time. Among persons 65 years of age and over receiving care at home, 25 percent have received care for over five years; 65 percent of those aged 65 to 75 and 73 percent of those aged 75 and over receiving care at home have received that care for over one year (U.S. Vital and Health Statistics, 1971). It is reasonable to assume that a comparable situation exists in the United Kingdom. Amelia Harris (1971) documented, for example, that older persons were less likely to be registered with a local authority than younger persons with the same level of handicap. Among persons with severe handicaps, 47 percent of those aged 16 to 49 were registered, 39 percent of those aged 50 to 64 in contrast to 9 percent of those 65 years of age or older. Further, a report on social work service in the United Kingdom (DHSS, 1973) notes that, while 80 percent of home health services are provided to older persons, the unmet need for such services is estimated to be two to three times greater than the amount actually provided.

These facts underlie increasing interest in community and home care in the United States and United Kingdom. Some older individuals currently in health care institutions do not need the level of care they receive, or could leave those institutions sooner if community and home care were available, or do not need to be there at all. Some individuals living in the community or at home demonstrably can be maintained there adequately with proper support services.

Experience suggests that two key support services in the community as first lines of defense against triage procedures which, once begun, tend to result in inappropriate types and levels of care are home health (usually nursing) and home help (a variety of domestic services). Although home health and home help services both have distinct tradition and focus, current practice stresses the importance of coordinating the two (Somers and Moore, 1976; International Federation on Aging, 1975). By way of emphasizing the importance to this coordination, current discussions of community and home care typically refer to "home health-home help" programs as a basic component of health care resources which should receive high priority. For this reason it is useful in this discussion to concentrate on "home health-home help" programs for older persons. We specifically recognize that the designation *community and home care* encompasses a broad array of services which we might but will not discuss, services which are as varied as home visits by physicians, meals on wheels, health centers, community mental health centers, special housing and transportation. Concentration on one type of service which is rather well documented will serve our purposes here.

A review of the relevant literature (e.g. Somers and Moore, 1976; International Federation on Aging, 1975; Calendar and LaVor, 1975; Hurtado *et al.*, 1972) suggests the following generalizations about "home health-home help services:"

(1) Western European countries, particularly the Nordic countries and the Netherlands, have extensive experience with both home health and home help services. The visiting nurse is typically an integral part of the health care delivery system in these countries and formal home help services have built upon established patterns of friendly neighboring and voluntary services.

(2) Experience has confirmed that such programs have special relevance for older persons. Older persons typically constitute about 75 percent of the clients of home health-home help programs; best estimates are that the need for such services exceed available service by at least a factor of two.

(3) The feasibility, indeed, the ease with which such programs can be estab-

lished and maintained, is well established. Appropriate personnel are available. Training procedures, curriculae, and materials are adequately documented.

(4) A substantial amount of experience exists regarding adequate personnel/population ratios, expected levels of demand, and approximate cost of home health-home help services. As a rule of thumb, experience suggests that one home health-home help full time equivalent is needed for every 100 persons 65 years of age and older. A few Nordic countries are currently near this ratio but most countries are quite distant from it. The ratio in the U.S., for example, is about 1:5000 and in the United Kingdom, about 1:750. Although data on average use of services and cost are very ephemeral and difficult to compare from one country to the next, two important conclusions emerge from current evidence which tend to allay concerns about unlimited demands for service and related high cost of programs: First, the length of time the average older person receives care services, the amount of services received; and second, the average cost of these services per case is well below comparable figures for long-term care in a nursing home setting.

Conclusions such as these have apparently been convincing in the United Kingdom. Home health-home help services in particular and more generally community and home care delivery systems are clearly an intentional integral part of national policy in that country. The intention is especially clear since the reorganization of the National Health Service in 1974. In contrast, consensus has not emerged in the United States regarding the role of community and home care services. To my knowledge, no one in this country argues that the need for such services has not been demonstrated or that such services are not feasible. Rather, the stumbling block appears to be the continuing commitment in the United States to a medical model of service delivery which features long-term care institutions and uncoordinated arrays of activities permitted but not facilitated by complex legislation and related administrative rules. When community and home care is permitted at all, an emphasis on medical certification and on the use of skilled professionals to provide the permitted services, presumably in the interest of controlling the cost rather more than the quality of service, is typical. This extreme cautiousness in the United States has resulted in minimal development of community and home care service. The most frequently stated reason for this cautiousness in the United States is cost. What is the evidence?

THE COST-EFFECTIVENESS OF NON-INSTITUTIONAL CARE OF OLDER PERSONS

Americans and Britains, it has been perceptively observed, are a people separated by a common language. One might add that they are also a people with very different interests in assessing the cost of health and welfare services. In the United Kingdom, where it would be feasible to design and implement research on the cost-effectiveness of various components of an integrated care delivery system, there is little interest in doing so. In the United States, where it is for all practical purposes impossible to implement adequate research on cost-effectiveness of a fragmented non-system of services, there is a preoccupation with cost.

The most compelling argument from the United Kingdom for increasing emphasis on community and home care remains largely implicit. This argument can be constructed as follows: The total national health bill in Britain is very favorable in comparison with other industrial countries. Costs have been contained in part by stressing primary health care and care outside specialized medical facilities; there has been some inconvenience but no demonstrable decrement to the health and welfare of the British people. Their health, for example, compares very favorably with the health of persons in the United States. The availability of community and home care services has not resulted in excessive new costs traceable to these services. This is the case in part because, even in the absence of restraints such as medical certification of services, average levels of utilization have been moderate; underutilization is more likely the problem than overutilization. Analysis of program costs and total system costs for these needed and apparently useful non-institutional services appear, therefore, to be tolerable. Continued development of such services does not depend on further demonstrations that they serve useful purposes, will be used appropriately in the absence of strict rules of certification or are more economical than institutional care.

In the United States the argument, both implicit and explicit, may be summarized as follows: Some older persons are hospitalized or are located in long-term care institutions unnecessarily and at a very high cost. Alternatives to

institutionalization surely can be found which provide more adequate care at lower cost. But commitment of more than a small fraction of our resources to these alternatives is not prudent because total system cost is already too high and because there is no effective way to control utilization. Consequently, we must convince ourselves that alternative types of care are cost-effective or, more specifically, that they are more economical than institutionalization.

There is more to this concern than meets the eye. Lay persons suspect what research investigators have demonstrated in the United States: Older persons receive the care they do, where they do, and when they do for a variety of reasons, only one of which is medical necessity. Consequently, sympathy can easily be generated for movements to de-institutionalize older persons even in the face of evidence that, for some older persons, the deinstitutionalization means less care or no care rather than better care (e.g. Arnhoff, 1975; Becker, 1976). The alternatives must be cheaper. The General Accounting Office of the United States has taken this position in a report to the Congress (1974), observing "several studies have pointed out that home health care *can be* (emphasis supplied) considerably less expensive than care in a hospital or a skilled nursing facility." What explains this cautiousness? The answer is supplied in part in a policy statement on Home Health Care by the Board of Governors of the Blue Cross Association (April, 1974):

"... (home health care) does not appear to create a cost saving to the community except as it may reduce the need for care in a nursing home facility. In fact, it appears to increase total cost of care because it represents an additional level of services which are necessary and appropriate in specific instances but do not, as a rule, reduce the need for other institutional types of health care services."

This statement makes a crucial point. Impact on total system cost of a particular type of program cannot be determined by concentrating alone on the cost of that program. Consider the research findings of Hurtado and his colleagues (1972) at the Kaiser-Permanente facility in Portland. Their research was designed to assess the impact on hospital utilization and the economic effects of introducing an extended care service and a home care service into a comprehensive prepayment health plan with a history of low hospital utilization by subscribers. The effect on hospitalization by Medicare patients was of special interest. The authors concluded that, with an extended care facility and home care service which were spatially and administratively an integral part of a comprehensive system of care, hospital utilization by Medicare patients could be reduced by 27 percent. They noted, however, that the reduced hospitalization was attributed principally to the availability of the extended care facility, not the home care services. Patients reported liking the alternative service; physicians were equally divided in their opinion. However, and this is very important, the total cost of total days in the extended care facility was greater than the saving attributable to reduced hospital days. Significantly, the report also stresses that the outcome of this demonstration in the economics of using alternative care facilities was affected substantially by spatial and administrative arrangements. At the beginning of the demonstration, the extended care facility used was not spatially and administratively integrated with the hospital; reduction in hospital days for Medicare patients was not achieved until the extended care facility was literally integrated into the hospital.

The conclusion suggested by the Kaiser-Permanente demonstration is that an integrated, comprehensive health service can utilize a variety of services, including home services, in the effective management of older patients. This can be done at a cost equal to or not much greater than the cost incurred by using a conventional hospital service. Community and home care for older persons is not the only consideration. If one could demonstrate that the physical, psychological, or social outcomes for patients managed in the community or at home were in fact superior to outcomes for patients who are managed in a conventional hospital service—and the report does not address this issue—the Kaiser-Permanente (Portland) demonstration would be important evidence in favor of an expanded range of services. The expanded services would not necessarily save money but would provide more value for money.

As a sobering reminder that, in the absence of an integrated system of care, costs can be quite variable and unpredictable, we should note a recent report to the Health Resources Administration (Trancentury, 1975) regarding the cost of ten daycare centers serving older persons. Daycare, the report indicates,

encompasses some programs which provide primarily social support services and other programs which stress rehabilitation. The average daily cost per client in these "daycare" programs reflected very different services and had a range from about \$11 to over \$60 with an average of about \$25. This average figure is much higher than the daily average cost for nursing homes, which was about \$16 in 1973-74 (U.S. Vital and Health Statistics, 1975). Nevertheless, the report concludes, that daycare is cost-effective because daycare patients are typically served only a few days each week in contrast to nursing home patients. Thus, the average monthly cost of daycare per older person is said to be economical. The report does not address several significant questions: Was the level of care given necessary and appropriate? Were the outcomes comparable to the expected outcomes for alternative modes of care? Did the provision of the services described change the total health care costs in the community attributable to these patients? The answers to these questions are not provided.

One need not quarrel with the good intentions of the proponents and providers of alternative community and home services and their hope that favorable outcome can be achieved economically. At the same time it is incorrect and misleading to argue that community and home care have been demonstrated to be economical; this has not been demonstrated.

My own best estimate is that, in the absence of a comprehensive, integrated system of health care, community and home care do not reduce total community costs. Whether stabilization or reduction of total cost is achievable through coordination remains an open question. An equally important question which has not satisfactorily been answered is the following: Can more effective care be provided to older persons in non-institutional settings as compared with institutional settings, holding cost constant: The quality of care and the cost of care should be discussed concomitantly. Preoccupation with the cost factor, however, may divert us from the central issue—the systematic coordination of services for older persons.

THE CENTRAL ISSUES: ORGANIZATION OF SERVICES

We have argued up to this point that community and home care for older persons are needed, feasible, and possibly, though not demonstrably, cost-effective. The unresolved issue of cost-effectiveness, we have argued, is symptomatic of a more and persistent basic issue: the organization of health care services for older persons. This observation is hardly novel. The United States and the United Kingdom present an instructive contrast in approaches and outcomes.

In 1971 the Department of Health, Education, and Welfare of the United States published a detailed critique of health care in this country and the diagnosis was bleak. Health care in the United States suffers not from lack of resources so much as from inadequate organization and distribution of resources. The delivery of health care, the paper concluded, was "a cottage industry of small entrepreneurs," "push cart vending in an age of supermarkets," in summary, a non-system. What was to be done? The prescription was complex and included potentially contradictory items. More primary and preventive care was stressed and Health Maintenance Organizations received very favorable notice. The intriguing suggestion was also made that, if one takes the economics of a free market generously, if one wants to affect health care, a major concern of national social policy should be the redistribution of personal income. Moreover, public dollars could probably do more for the public health if they were devoted to improving housing and nutrition than to medical research and hospital care. There was no mention of community and home care as such and only an incidental reference to the health care of older persons. Lest you think the authors of this document were totally out of touch with political reality, the White Paper begins by announcing a preference for keeping health predominantly in the private sector and for a national but not nationalized system of health care.

Five years later, the United States has not enacted national health insurance; has had to tamper incessantly with its basic Medicare regulations; has apparently immobilized Health Maintenance Organizations with very restrictive legislation; has developed a policy of de-institutionalization without insuring provisions for alternative sources of care; and has not developed an effective program for developing personnel and mechanisms to insure adequate care of

older people. In the light of such non-performance, we would be surprised if community and home care for older persons were established as part of national policy. But there are no surprises here; community and home care continue to be discussed as though their merits still had to be established. The future of geriatric health care services both in institutions and outside institutions is very much in doubt. Lack of resources, in my estimation, is not the problem. Our non-system of health care is the problem.

The situation in the United Kingdom provides sharp and instructive contrast. The British National Health Service has its problems; but it represents a considerable organizational achievement as a comprehensive, integrated system of services which has been particularly responsive to the health care needs of older persons. Reorganization of health care in Britain, we should note, did not come easily. Impetus for the creation of the National Health Service was the imminent collapse of medical care delivery prior to the First World War (Eckstein, 1958). The organization which emerged in 1948—an organization committed to free access to care, salaried practitioners, and a team approach to care—proved to be remarkably stable and economical over the next two decades. It was my good fortune to study in Britain in 1968 as a U.S. Public Health Service Research Fellow at a time when various Royal Commissions were assessing the work of the first twenty years.

The major points of criticism were evident in widely circulated reports on every aspect of health and welfare services: Control of further medical specialization and renewed emphasis on primary care were needed; geographic redistribution of care was required; the ratio of hospital beds to population needed to be reduced and alternative care settings provided; and most of all, the separation of medical, health, and welfare services was intolerably ineffective and required a new integration. In 1968, the United Kingdom was well on its way to the Reorganization of 1974. Since this American was in London to study how a Labour government with a Fabian interest in effect management made and implemented health policy, he admits having been disconcerted by the heavy reliance of National Health Services planners and managers on what might be called the testimony of experienced men in contrast to information based on social scientific research. Health planning in the United Kingdom was indeed captured in phrases like "muddling through" and "disjointed incrementalism." Yet, the observed scientifically inelegant planning procedures generated, or so it appeared, a sound and effective health care organization which was delivering value for money (Maddox, 1971). It was my impression then, as it is now, that the United Kingdom has very few health problems that adequate financing could not solve. A similar conclusion is reached in a recent analysis by Anne R. Somers (1976). In providing "an American perspective" on the National Health Service, she documents the major characteristics which insure that geriatric care is an integral part of the total service.

General practice has continued to be emphasized and provides access to primary and preventive care. Geriatric medicine is a recognized specialty. "Alternatives to institutionalization" is not a slogan but a policy which is actively implemented by programs of visiting nurses, home help, health centers, day care and day hospital centers, special transportation, and special purpose housing. Mrs. Somers also makes an insightful comment about the philosophy of care in the United Kingdom which she describes as an amalgam of public preference and traditional ways of practicing medicine. This philosophy continues to stress free access to care, primary and preventive care, and non-institutional care. In this environment we would be surprised if community and home care for older persons were not observed.

In summary, barring total financial disaster in the United Kingdom, community and home care for older persons will thrive as an integral part of the National Health Service. In the city of Glasgow under the leadership of Sir Ferguson Anderson and his colleagues, one can observe today the most complete array of services in the world and operated at a bearable cost. Glasgow provides an excellent "for instance" when one is conceptualizing a system of care which is designed to meet the health care needs of an aging population.

In contrast, in the United States, demonstrations of the unmet needs of older persons of the probable cost-effectiveness of community and home services are unlikely to produce the needed services until an integrated system of health care and health care financing is achieved. And when that system is achieved, it is my prediction that it will look remarkably like the British National Health Service.

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ASSESSMENT OF INDIVIDUAL FUNCTIONAL STATUS IN A PROGRAM EVALUATION AND RESOURCE ALLOCATION MODEL¹

(By George L. Maddox, Director, Duke University Center for the Study of Aging and Human Development)

The social and political visibility of health and welfare programs has increased markedly in recent decades in the United States as numbers of participants and costs have escalated. Concomitantly, interest in the efficiency and effectiveness of health and welfare services and of the procedures for allocating scarce resources to these services has generated a special concern for developing and refining measures of program performance and the impact of allocations to alternative programs (Rivlin, 1971; Maddox, 1972). This paper outlines a model designed to facilitate program evaluation and decisions regarding resource allocation. The focus of the paper, however, will be on the first element of this model—the measurement of the functional status of individuals who compose the populations for which programs are developed and resources are allocated. A brief word about how the model developed is in order.

In 1972 the Duke University Center for the Study of Aging and Human Development was asked by an agency of the U.S. Government to structure and conceptualize an approach to understanding a persistent issue of special relevance in an aging society—alternatives to institutionalization, or better, institutionalization as an alternative in a continuum of health and welfare services. The occasion for what was presented as a rather urgent request was the juxtaposition in the minds of citizens and legislators of over one million long term care beds occupied primarily by older persons at the cost of over eight billion dollars in public funds annually and continued reports that high cost was not insuring quality care (Maddox, 1972; Shanas and Maddox, 1976). The fact that national wealth does not insure a nation's health and well-being was bad enough; the idea that public investments might decrease well-being was intolerable.

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Our attempt to structure the problem of institutionalization as an option in a system of services led us to conceptualize a basic model which, we believe, is not only useful in approaching the specific question of options in long term care but also has general applicability to program evaluation and to resource allocation decisions. This model has three critical elements:

(1) A procedure for measuring the functional status of individuals and a related scheme for classifying individuals with similar status (equivalency classes);

(2) The disaggregation of services into their generic elements in a way which permits comparison and costing across the particular aggregations (service packages) as they appear naturally in various programs; these procedures would permit analytic differentiation of services both from the organizational locale in which they are offered and from the particular person who provides the services (See Pfeiffer, 1975b; Burton, Damon and Dellinger, 1976); and

(3) A matrix which permits an analysis of the hypothetical or actual impact of alternative service programs (service packages) or particular organizations of generic service components on any identified array of individuals classified in terms of equivalent functional statuses (Burton, Damon and Dellinger, 1976).

This paper concentrates on the first of these three elements and will stress the logic of a measurement procedure and its related classification scheme. The details of the second and third elements of our model will be explicated in subsequent papers, although we will indicate and illustrate briefly in this paper how our procedure for measuring and classifying older individuals in terms of functional status relates to the other elements. We stress our focus on the functional status of individuals for a specific reason. Program evaluation and resource allocation decisions cannot be done adequately in the absence of information about the functional status of individuals. Moreover, a review of behavioral and social scientific literature makes abundantly clear both that adequate research on the impact of programmatic interventions requires simultaneous macroanalysis of the social context of social programs and a microanalysis of individuals in those contexts and that such simultaneous analysis is extraordinarily uncommon (Hernes, 1976).

CONCEPTUALIZING THE FUNCTIONAL STATUS OF INDIVIDUALS: THE FIRST ELEMENT

The reliable, valid and adequate characterization of individuals which can also be accumulated to describe populations in ways simultaneously useful to clinicians familiar with older persons, to program analysts, to resource allocators, and to research scientists in a variety of disciplines is a major objective of the Duke project. Improbable as the development of such a classification procedure may seem, failure to do so compromises consequentially, perhaps fatally, procedures for program evaluation and resource allocation. Our interest in characterizing populations and individuals simultaneously presented, of course, some special problems in instrument development. For our purposes, we required an instrument that had to be relatively brief and easy to administer in the field as well as in clinics. It had to be satisfactory to clinicians as well as to research methodologists. Further, the data to be collected had to be sufficiently detailed to differentiate functioning between individuals at a point in time and within individuals over time but reducible to a limited number of meaningful and manageable categories. The task was obviously formidable.

Our initial review of the existing literature on client classification and our experience with the first three hundred clients in the Duke Center's information, referral and counseling service for older persons indicated that the instrument we required did not exist and suggested why this was the case. Older clients who seek help typically present multiple problems—problems which reflect various degrees of impairment in physical health, in mental health, in their capacity to carry out the self-care requirements of everyday life, and in the social resources and the economic resources which can compensate in part for their personal incapacities. Limited purpose instruments were identified which addressed one or two types of impairments but never all of them; and the available instruments only occasionally addressed and certainly did not resolve adequately issues of reliability and validity (See e.g., Katz and Lyerly, 1963; Williamson, 1971; Gurel, Linn and Linn, 1972; and Gurland et al, 1972). Moreover, the available literature frequently concentrated on diagnosis of particular health conditions or the identification of particular impairments rather than on assessment of functional status. Our experience and our conceptualization of the most useful way to characterize individuals and populations for our purposes was to concentrate on a multidimensional measure of functional status (See, e.g. Fanshel

and Bush, 1970, and Strole *et al*, 1962). This approach appeared to be appropriately flexible and to focus on the summary of individual and population characteristics of paramount common interest to clinicians, research scientists, program analysts and resource allocators—the functional capacity of individuals to carry out usual social roles in a competent and personally satisfying way.

The demanding task we set for ourselves necessarily involved some strategic compromises. Experts in our research group with experience in assessing physical or mental health, economic resources, social relationships or activities of daily living inevitably wanted more detail than was in fact possible. Defensible compromises and accommodations were made in the interest of developing a manageable assessment instrument which can produce a reliable, valid classification of functioning in five areas and can do so in 35 to 40 minutes. The instrument we developed and have used in our assessment clinic and in community surveys includes, in addition to certain demographic and screening information, a Part A which concentrates on functioning in the five dimensions of interest and a Part B which concentrates on the perception of needed services and a report on services used. The total instrument requires about 70 minutes to administer with the time distributed almost equally between Part A and Part B. Additional details are provided in an appendix to this paper.

MEASURING FIVE DIMENSIONS OF INDIVIDUAL FUNCTIONING

Our pilot studies took us through numerous iterations of questions designed to assess five dimensions of functioning: (1) physical health; (2) mental health; (3) economic resources; (4) social interrelationships; and (5) activities of daily living (ADL). Although our experience suggested that these dimensions were discrete and importantly different dimensions of functioning, we are pragmatic rather than doctrinaire on this issue. We now have relevant data from a relevant study population of 997 randomly selected community-dwelling persons 65 years of age and older (Table 1). The intercorrelations among the various dimensions is modest, with the highest correlations being between physical and mental health (+.53) and between those two dimensions and ADL (+.54 and +.55 respectively).

TABLE 1.—PRODUCT MOVEMENT: CORRELATIONS AMONG THE FIVE DIMENSIONS OF FUNCTIONING

	Economic	Mental health	Physical health	ADL
Social.....	0.30	0.38	0.21	0.16
Economic.....		.39	.29	.26
Mental health.....			.53	.55
Physical health.....				.54

Source: Information based on 997 randomly selected community residents aged 65 and over (Pfeiffer, 1975b).

Our consultants or colleagues have occasionally argued that the various dimensions contribute differently to overall functioning and/or that economic resources and social relationships are contextual factors which are conceptually different from the other three dimensions (e.g. Williams, 1974). Perhaps this is so but the issue should be resolved by evidence and theoretical perspective. Our strategy has been to conceptualize and to store our data in ways which maximize our options for subsequent analysis of data.

In developing questions which would tap essential aspects of each of the five dimensions, we drew as often as possible on a wide variety of previously reported items. The various iterations of our pilot questionnaire provided data which permitted assessment of the discriminant value of each question. The result—the Multidimensional Functional Assessment Questionnaire (MFAQ)—provides a reasonably reliable and valid assessment instrument which can double adequately as a clinical intake procedure and as an epidemiologic survey questionnaire, which can be administered and scored by a minimally trained individual, and which is economical and flexible from the point of view of data management.

The basic structure of the MFAQ is described briefly in an appendix to this paper and conveniently reproduced and described in detail in Maddox and Karasik (1976) and Pfeiffer, *et al* (1975b & 1976). As we have noted, the MFAQ is divided essentially into two equal parts; our attention here focuses only on Part A (functional status). We assessed level of functioning in each of five dimensions, the final assessment being made for each dimension by the inter-

viewer on a six point scale precisely defined by criteria for each of the six points. The continuum ranges from unimpaired functioning (1) to total disfunction (6).

Reliability.—We had considerably more than a ritualistic interest in establishing the reliability of function assessment based on the MFAQ. There was no bank from which to draw appropriate questions or scales whose reliability had been previously established. And our experience in policy analysis convinced us that research purporting to be applicable to significant societal issues not only should be reliable but also has a high probability of being effectively challenged and disqualified when evidence of unknown reliability is introduced (Maddox and Karasik, 1976, pp. 1-10). In the case of the MFAQ, inter-rater reliability is acceptably high with an average agreement over all five dimensions of 0.80 and a range of .74 (mental health) to .88 (physical health).

When inter-rater reliability is compared by disciplinary training, social workers achieved .86 agreement (range, .77 to .93); psychiatrists, .85 (range, .82 to .89); and research methodologists, .80 (range, .70 to .89). In a personal communication, William Laurie of the Cleveland Office of the U.S. Government Accounting Office, who has just completed a large sample survey using the MFAQ, reports that inter-rater reliability in his study is a comparable .85. Although we continue to use experienced raters in the determination of functional status, the possibility of machine scoring of questionnaires in large sample surveys is being explored and preliminary work is encouraging.

Validity.—The procedure used to evolve MFAQ provides some assurance of the face validity of the questions selected to assess the functioning of individuals in the five dimensions. The research team included research investigators and clinicians from a variety of disciplines who had had considerable exposure to both the relevant literature on client assessment and to older persons in institutional, clinical, and long term care settings. Additional information on validity of classifications derived from the MFAQ is provided by a comparison of functional ratings of individuals on the five dimensions by intake interviewers using only the questionnaire and assessment on the same individuals by a clinician in an in-depth interview. Mean assessment ratings derived from both procedures are essentially the same for four of the dimensions, the exception being the ADL dimension.

The clinical interview produced a significantly lower ADL assessment. Finally, the MFAQ has been used with three samples of older persons who presumptively should have substantially different distributions of functional impairment—a random sample of community-dwelling older persons, a random sample of institutionalized older persons and clients in an outpatient geriatric assessment clinic (See Pfeiffer, 1975b). While there is expectedly some overlap in the distribution of assessed impairment in these samples, the MFAQ produces distributions whose distinctly different means and modes are expected. The community subjects are appropriately in between. As we have noted above and will note again below, the reliable, valid assessment of individual functional status is but the first essential element in our model. The third element, a transition matrix, conceptualizes the ultimate issue regarding validity of measurement—the capacity to predict the probabilities of stability and orderly change in individual functional status over time under specified conditions. We are currently at work on the issue on predictive validity of the MFAQ.

THE FUNCTIONAL CLASSIFICATION SCHEME

Our attention now shifts to problems of data reduction. The initial reduction involves, as noted above, translating reliably from multiple questions regarding each dimension into five summary measures on six point scales. That further reduction is required is suggested by the number of different functional profiles which are potentially possible from these observations alone—7.776 (6^5). This number is clearly impractical for purposes of analysis. We have settled, in the short run, for a manageable scheme which dichotomizes the six point scale as unimpaired (1-3) and impaired (4-6) for each of the five scales resulting in 32 (2^5) profiles or equivalency classes. Thus an individual who is assessed to be unimpaired on all dimensions is in equivalency class 1 and one who is impaired in all dimensions is in class 32; the other thirty logic combinations range in between these extremes. For purposes of follow-up in any defined population, we have added an additional category to indicate death.

We are not at this time prepared to specify on the basis of evidence currently available to us the normative distributions of older population among our equivalency classes or to demonstrate the substantive significance of the observed

combinations of impairments. We do know that, in two populations which have been studied, 30 of the 32 possible equivalency classes have entries and that individuals are not randomly distributed among the classes. We are thus in a position to concentrate on the second element of our model—the generic services and their aggregation as service packages—and eventually on the third element—the outcomes which are expected or observed when persons of known equivalency classes are exposed to identified service packages.

In the short run we are in a position to use the observed distribution of functional impairments in each of the five dimensions to characterize populations and sub-populations of older persons differentiated by age, ethnicity, rural-urban residence, and ethnicity. We know already, for example, that in a random sample of Durnam County (N.C.) elderly, 9% are impaired in social resources; 13% in terms of mental health; 14%, economic resources; 21%, ADL; and 25%, physical health (Pfeiffer, ed., 1975b). From preliminary data in a comparable study of a random sample of 1,609 elderly persons in Cleveland, Ohio to be reported shortly, use of the MFAQ produced an almost identical distribution of impairments.

Another procedure for data reduction that we have found useful is the Cumulative Impairment Score (CIS). This score sums the position of an individual on the six point scale for each of the five dimensions; the CIS thus can range from 5 (unimpaired) to 30 (totally impaired), with a mid-point of 17.5. The use of the CIS to describe the distribution of, say, a community-dwelling sample and a sample of long term care residents will produce significantly different mean CIS scores and little overlap in the distributions. With such information it is possible to explore whether individuals in the overlap category (low CIS scores for institutional residents and high CIS scores for community-dwellers) can be explained by the different configurations represented by the different equivalency classes.

SOME CURRENT AND POTENTIAL DEVELOPMENTS OF THE MODEL

Although our ultimate interest is in articulating our program evaluation and resource allocation model, the MFAQ has been immediately useful in several ways. It is currently being used as an initial screening and intake instrument in the Duke Center's Geriatric Assessment Clinic, an affiliate of the county community mental health clinic. The MFAQ is similarly used at intake for all patients over 65 years of age in the ambulatory clinic of Duke's Family Medicine Program; in this instance the instrument is part of a research-demonstration project designed to assess the impact of information about patient functioning on chart entries and management plans made by family medicine residents who have functional status profiles of their older patients at the time those patients are seen for the first time.

Since the MFAQ has been used in clinics and in epidemiologic surveys of random samples of community-dwelling and institutionalized older populations, the profiles of these various populations can be usefully compared in terms of observed distributions of functional impairment.

The information from our own county survey is, for example, appropriate for responding to the initial question which every service organization in the United States is required to answer when applying for public resources: Is there a need for your services? MFAQ data can be compared with known participants in existing programs to identify untreated impairment. We hasten to add, however, that we do not consider the MFAQ as a "needs survey" instrument. Need is a second-order construct, a judgment made by someone evaluating what we consider to be the first-order construct, impairment. We do not think it is useful to interchange casually impairment and need because the perception of an impairment as a need is a complex judgment; further, the decision to translate a need into a condition warranting social intervention involves social preferences.

Consider, for example, the problem of a policy analyst or resource allocator. Given that some impairment is inevitable, what is a desirable—or preferred—distribution of individuals among the equivalency classes as we have conceptualized them? If a preferred distribution is identified, our classification scheme suggests options for programmatic intervention directed to changing the population profile in a preferred way. Our strategy of conceptualizing the problem makes it clear that social preferences involve political and economic considerations. Both considerations are involved in resource allocation and our procedure is designed to provide relevant information without prejudging what those social preferences should be.

Although we are still a considerable distance from the routine application of our model, some significant advances have been made. A reliable, valid instru-

ment for measuring and classifying individuals in terms of functional status exists. In addition to this first element of our model, preliminary work at Duke and by colleagues in the U.S. Government Accounting Office in Cleveland, Ohio, indicates that our strategy for conceptualizing generic services can be reliably applied in disaggregating the services offered by a variety of organizations serving older persons and reaggregated then to describe the services being offered to individuals whose functional status is known. We therefore have the essential elements to proceed to the third step in our model—the impact of defined service packages on individuals whose functional status is known or on equivalent classes of individuals (Burton, Damon and Dellinger, 1976).

Of immediate interest is the important research now underway under the direction of William Laurie of the Cleveland Office of the U.S. Government Accounting Office. Using the Duke MFAQ and the related generic services classification, Laurie and his associates have been able to combine in the same data file 1) the initial functional status of a sample of a defined population ($N=1,609$; 2) the generic services offered to this defined population over a period of a year by essentially every health and welfare organization in the relevant geographic area (including Medicare, Medicaid, and the Veterans Administration); and 3) the functional status of the defined population one year later.

A pertinent illustration of the utility of our transition matrix—point three of our model—is therefore imminent. This illustration from Cleveland is most accurately described as an exercise in program evaluation. That is, it is an exercise in demonstrating the impact of current allocations for service programs. But, with such information, the next possible step would be an exercise in deliberate alternative resource allocation in the interest of modifying a population's functional status profile in preferred directions. We do not minimize the problems inherent in deciding what constitutes a preferred direction. That decision is fundamentally a political, not just a professional, decision. We argue here only that our model suggests a useful way of structuring the decisions and providing relevant information.

A FINAL NOTE

The title of this session is "Health Research: Its Communication and Utilization." In these closing paragraphs, I wish to relate this presentation and the experience it summarizes explicitly to the session topic.

The persistently ineffective communication of health research to potential users and the non-utilization of that research in the United States are facts, one might even say scandalous facts. The reasons for this state of affairs are multiple and complex. Our experience (See Maddox and Karasik, 1976) suggests some of these reasons and I have given hints throughout the presentation which should not be made explicit.

First, what various consumers of health and health systems information—clinicians, program evaluators, and resource allocators—want to know or need to know often is not available or cannot be supplied by the research community. Our capacity to measure key variables in the behavior of individuals and organizations remains profoundly primitive and far short of the standards of reliability and validity which a critical consumer wants and has a right to demand. The situation is noticeably improving, however.

Second, increasingly reliable, valid, and systematic information about health and health systems is a critical advance but will not in itself insure adequate communication or utilization of information. The disciplinary organization of information is a major impediment with which our own multidisciplinary research team struggled continually. And our internal difficulties in cross-disciplinary communication were minuscule when compared with problems of translating our conceptual scheme, procedure, model and findings variously and often simultaneously to physicians, nurses, social workers, methodologists, economists, systems analysts, program manager, and citizens at large. Differences in intellectual perspective are real and they are consequential. Differences in value perspectives are equally real and consequential. These value differences are at the heart of the inevitable political implications of health research. Academically oriented research investigators are obviously uncomfortable with the way in which facts and value preferences intermingle in policy-relevant research but they forget this fact at their peril. Powerful incentives exist in social and political systems to suppress or ignore inconvenient information and to dismiss inconvenient information whose reliability and validity are questionable. Inconvenient information which appears to be reliable and valid can be perceived as threatening to existing

commitments. The ambivalence which rational and responsible resource allocators have for research is real and has some basis in their experience.

Third, in the United States there exists an almost universal organizational fact which tends to insure that research ostensibly intended to be useful in planning services is almost never used effectively. This organizational fact is the separation of the responsibility to plan and the authority to commit resources. Such a separation perpetuates the isolation and adversary relationships which we observe between planners and social program managers. The attendant problems include not only the failure of planners to develop and communicate effectively what they know but the failure of program managers to communicate effectively what they need to know soon enough for planners to be helpful. Based on our own experience, we have concluded that an invitation to do research which is relevant to health policy is probably most adequately conceived as an opportunity to address future policy issues rather than the policy issue for which the initial request is made.

In addition to basic demographic and interview specific information the questionnaire consists of two sections: Part A, Assessment of Individual Functioning and Part B, Assessment of Services Utilization.

PART A : ASSESSMENT OF INDIVIDUAL FUNCTIONING

Part A is divided into seven major sections. These sections, in order, with number of primary questions (some questions include several items) and descriptions of question content are:

[ATTACHMENTS I]

Section	Number of questions	Content
Basic demographic.....	11	Address; date; interviewer; informant; place of interview; duration; sex; race; age; education; telephone number.
Social resources.....	9	Marital status; living companions; extent and type of contact with others; availability of confidante; perception of loneliness; availability, duration, and source of help.
Economic resources.....	15	Employment status; major occupation of self (and of spouse if married); source and amount of income; number of dependents; home ownership or rental, and cost; presence and adequacy of financial resources; health insurance; subjectively assessed adequacy of income.
Mental health.....	6	Short portable mental status questionnaire (SPMSQ, Pfeiffer, 1975a, a 10-item test of organicity); extent of worry, satisfaction, and interest in life; assessment of present mental status and change in the past 5 yr; 15-item short psychiatric evaluation schedule.
Physical health.....	16	Physician visits, days sick, in hospital and/or nursing home in past 6 mo; medications in past month; current illness and their extent of interference; physical, visual and hearing disabilities; alcoholism; participation in vigorous exercise; self-assessment of health.
Activities of daily living.....	15	Extent of capacity to; telephone; travel; shop; cook; do housework; take medicine; handle money; feed self; dress; groom; walk; transfer; bathe; bladder and bowel control. Also, presence of another to help with ADL tasks.
Informant assessment.....	10	Information on the focal person's level of functioning on each of the 5 dimensions is sought from a knowledgeable informant. Specifically: Social: Capacity to get along with others; availability, duration and source of help in time of need. Economic: Extent to which income meets basic self-maintenance requirements. Mental: Ability to make sound judgements; cope; interest in life; comparison with peers; change in past 5 yr. Physical: Assessment of health; extent of interference of health problems.
Interviewer section:		
(a) Interview specific.....	4	Sources of information; reliability of responses.
(b) Interview assessments.....	15	Social: Availability and duration of help care needed; adequacy of social relationships. Economic: Assessed adequacy of income; presence of reserves; extent to which basic needs are met. Mental: Ability to make sound judgements; cope; interest in life; behavior during interview. Physical: Whether obese or malnourished. Rating scales: 5 6-point scales, 1 for each dimension.

¹ Prepared by Dr. Gerda Fillenbaum, senior fellow, Duke University Center for the Study of Aging and Human Development.

PART B: SERVICES ASSESSMENT

For each of the 24 non-overlapping services named below enquiry is made into (a) utilization in the past 6 months; (b) intensity of present utilization (e.g., frequency cost); (c) service provider (e.g., self, family and friends, agency); and (d) perceived current need for service.

- | | |
|---|--|
| 1. Transportation | 14. Continuous Supervision |
| 2. Social/Recreational | 15. Checking |
| 3. Employment | 16. Relocation & Placement |
| 4. Sheltered Employment | 17. Homemaker-Household |
| 5. Educational Services, employment related | 18. Meal Preparation |
| 6. Remedial Training | 19. Administrative, Legal & Protective |
| 7. Mental Health | 20. Systematic Multidimensional Evaluation |
| 8. Psychotropic Drugs | 21. Financial Assistance |
| 9. Personal Care | 22. Food, Groceries |
| 10. Nursing Care | 23. Living Quarters |
| 11. Medical | 24. Coordination, Information & Referral |
| 12. Supportive Services and Protheses | |
| 13. Physical Therapy | |

ORDER OF ADMINISTRATION

The general order of administration follows the section order given above, except that the SPMSQ is given first and acts as a screener, so that the interviewer can determine whether to continue interviewing the focal person or whether an informant is essential.

When information is desired from both Parts A and B, Part B is administered immediately following the ADL section. Total administration time is approximately 70 minutes, the time for Part A taking 35-40 minutes.

ASSIGNING RATINGS ON THE BASIS OF QUESTIONNAIRE DATA

The information gathered is intended to be condensed into level of function ratings, one rating being assigned in each of the five dimensions (social, economic, mental health, physical health, ADL). In classifying individuals trained raters read through the material in the relevant sections and then assign a rating. Inter-rater reliability is facilitated by having both an adjectival marker for each point of the scale of functioning (1=excellent; 2=good; 3=mildly impaired; 4=moderately impaired; 5=severely impaired; 6=totally impaired) and a descriptive paragraph detailing the conditions which have to be met before a particular value can be assigned. These conditions are tied to specific responses in the questionnaire.

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ITEM 6. CORRESPONDENCE BETWEEN LOUISE M. BIGGS, SALMON, IDAHO, AND SENATOR FRANK CHURCH

SALMON, IDAHO, *June 15, 1977.*

Senator FRANK CHURCH,
*Russell Office Building,
Washington, D.C.*

DEAR SIR: The past 5 years, I have been involved in the public health field as a secretary. There are many programs in this field, but one of the most worthwhile to be instituted in this country has been Home Health Care.

When this program first came to this country, I was elected secretary to the Home Health Care Advisory Board and therefore, am very involved with this program and its success. At this time, I no longer work in that particular position, but am still highly interested in public health.

As the Home Health Care program evolved over the years, I watched the paperwork of the nurses increase due to added regulations. This made less time for actual patient care. There is one ruling in particular which disturbs me greatly and that is Medicare's ruling on what they term, "custodial care." If many of the patients in this country could receive care in these instances where the family wishes to care for their own, we would be doing a great service to humanity and the country. Some people lose all interest in living when put in an institution for "custodial care." Oftentimes, this is the only recourse left to a family when the care provided through Home Health Care has been regulated out. If they could have relied on Home Health Care, it may have held a family together. This is the other aspect of Medicare that disturbs me. By some of their regulations, responsibility of the family to its members is negated because they cannot cope without some professional assistance nor can they afford long-term care in a hospital due to costs. For some, the breaking up of the family is an agonizing decision, and the breakdown of their independence. Breakup of the family unit affects all the members, not just the ill person, and self esteem is so lowered as to cause a multitude of other problems in the family which eventually become the responsibility of government. Often, this is not necessary! With just a little help, these people could have stayed together.

I am asking that you do all you can to sponsor legislation that will allow families and their personal, long-standing physicians decide their care plan and instruct his Home Health Care personnel how to carry out the plan in the best interests of the patient. No patient is the same and even with the same diagnosis, therefore, set guidelines cannot possibly be flexible enough to fit most people's needs.

There is so much to say for this program, I couldn't possibly get it all in one letter nor can one describe the benefits experienced by the family nor the grati-

fiction the personnel feel in helping their fellow man. Please do something to hold this program, governed by Medicare regulations, to a sensible and practical minimum. Costs, I am sure, would not increase if city, county or even the state could somehow be more involved in regulation. We in Salmon live a unique way of life, and therefore, regulations set in Washington, D.C. or Boise, Idaho cannot often be applied.

Your interest is much appreciated. Thank you for your consideration on this matter.

Sincerely,

LOUISE M. BIGGS.

JULY 13, 1977.

MRS. LOUISE M. BIGGS,
Salmon, Idaho.

DEAR MRS. BIGGS: I want to thank you for your excellent letter outlining problems in Medicare regulations which make it difficult for family members to stay together.

As you can see from the enclosed statements, the Committee on Aging, which I chair, has just completed a series of hearings on alternatives in long-term care for the elderly. With your permission, I would like to include your letter and any additional comments you may wish to make as part of the hearing record.

One of the challenges we are now faced with is finding ways to provide incentives within health and social service programs to make it easier for families to care for their elder members, and I think your letter makes an eloquent statement of the need for such action.

With best wishes,
Sincerely,

FRANK CHURCH, *Chairman.*

SALMON, IDAHO, *July 21, 1977.*

Senator FRANK CHURCH,
Russell Office Building,
Washington, D.C.

DEAR SIR: Thank you for the information on "Health Care for Older Americans—The Alternatives Issue," along with your letter of July 13, 1977.

Of course, you may include my letter to you June 15, 1977 as part of your hearings and add this letter as additional comment.

Since I last wrote, several more incidents have come to my attention which may be of interest to you.

Some patients who could use home health care nursing services do not fit into Medicare guidelines, although the local physicians have directed Home Health Care personnel to attend the patient. An example would be a 90 year old woman who needs Vitamin B-12 injections and her vital signs monitored. She is very low income and cannot afford private nursing care or a nursing home, which she wishes to avoid. Nor can she give herself injections. She can manage at home with this little bit of care. Medicare guidelines say "no." What is the nurse to do; tell the lady, "sorry, you don't fit the guidelines—we can't help you!" Her health has steadily deteriorated without thrice weekly injections. Here is a distinguished lady by right of her old age with a legacy of years and knowledge which will be lost to us because she is failing quickly without the care she needs and her physician prescribed. And it is not only this one person; think of countless others in the same predicament all over the United States.

The second example is an older person who needs to be monitored to make sure she takes her medication. The nursing visits are important to her to keep her anxiety level low, which in turn affects her blood pressure. She needs to know she is cared about and that she is taking her medications correctly. With a blood pressure check, she feels secure. However, Medicare regulations do not cover mental health nursing, which in essence, this would be. You know Senator Church, there are a lot of old people in the world who are or seem to be emotionally ill or senile because they feel no one cares and what's the use. Institutions are full of people who only need minimal attention; and attention is the key word here. Why must we neglect our elderly and categorize them. Can anyone put a unique human being into a category? Everyone is different with different needs and only through interpersonal action and care can one determine what they need.

Can you see the point of revising Medicare regulations, for in the main, they support the Home Health Care program in this area as we are definitely a low income area. Patients cannot pay out of their pocket for care. Social Security payments just do not cover all their needs. These people worked and paid their Social Security in trust that they would be cared for in their old age. But, as you well know, they are not being cared for through no fault of their own because they were assured Social Security was their retirement income. Can you imagine their letdown! Often, I wonder if this has changed their feelings towards their country.

You can see that I do care what happens to our elderly and the frustration caring people run into when trying to help. I am sure you share this frustration in attempting to untangle the multitude of Medicare regulations. Good luck to you and your committee!

If I can be of further assistance, please feel free to call on me. Attached for your convenience, is a copy of my first letter to you.

Sincerely,

LOUISE M. BIGGS.

ITEM 7. STATEMENT OF THE DAY HOSPITAL, BURKE REHABILITATION CENTER, WHITE PLAINS, N.Y.

INTRODUCTION

We at the Burke Rehabilitation Center Day Hospital have found that the term "alternatives" is misleading because it implies that institutional care is necessarily undesirable. Institutional care has a significant role in our health care system, provided it is the appropriate placement. It becomes undesirable when it is the only alternative available and is not appropriate. We believe that every community needs a variety of health care options and community services that constitute a continuum of care. An individual can then move in and out of the setting which is most suited to his particular needs. We view the day hospital as one health care option within a continuum of care.

A day hospital is a "hospital without beds." It is essentially a medical rehabilitation facility without the "hotel" element of hospital care. Its goal is to restore the individual's capacity to perform as many of the activities of daily living as possible, to reduce feelings of helplessness, to rebuild or increase self-confidence, to improve the capacity of patient and family to cope with problems, to enable them to remain in the community and be capable of directing their own lives.

THE BURKE REHABILITATION CENTER

The Burke Rehabilitation Center is a 150-bed voluntary, non-profit rehabilitation hospital located in White Plains, New York. It is Joint Commission-accredited and is affiliated with the Cornell University Medical Center. Burke offers comprehensive multidisciplinary physical medicine and rehabilitation services to inpatients and outpatients. It was first opened in 1915 as a convalescent home, but in 1951 it became a major rehabilitation center.

THE BURKE DAY HOSPITAL

The day hospital, developed at Burke and currently operating there, is a medical model. Its goals are similar to those of the British geriatric day hospital, viz., rehabilitation of its patients, ongoing medical/nursing supervision, socialization, and relief of family stress and strain.

EVOLUTION OF BURKE DAY HOSPITAL

In 1963, the Burke Board of Directors' Long Range Planning Committee established a Chronic Illness Study Group for the purpose of assessing the unmet health needs of aging and chronically ill adults in Westchester County, and to determine Burke's future role in meeting some of those needs. The major recommendation of this study was that Burke establish a day hospital. These conclusions were based on a needs analysis, a survey of community programs, and the experience gained in coordinating an 18-month pilot community home care program as part of the Chronic Illness Study. The Burke Board postponed action on the establishment of the recommended day hospital program because of insufficient space and lack of necessary funds.

Four years later, however, a study of the Center's physical facilities resulted in the construction of a new 3-story wing which provided for the total replacement of Burke's 150 inpatient rehabilitation beds. Upon its completion in September, 1972, two former inpatient buildings were vacated. One of these was scheduled to be modernized for expanded administrative services, thus leaving one building for which no immediate plans had been made. With the availability of physical space imminent and the need for day care services more apparent than ever, a survey was made in 1971 by the Center's Planning and Program Development staff to update the information gathered eight years earlier. The findings of 1963-64 had not changed substantially. The aging, chronically ill population had increased, services had become more fragmented, and the need for a day hospital had become more urgent. More evident than before was the need to coordinate and make accessible a comprehensive package of health care services for those chronically ill, physically disabled aging persons who did not require 24-hour institutionalization.

With this goal in mind, DHEW Medical Services Administration Office of Innovative Programs was approached for funding of a research demonstration project which would test the viability of the day hospital concept in this rehabilitation setting. They were responsive to the idea and suggested that it be co-funded by the Administration on Aging. A 3-year research demonstration grant was awarded on July 1, 1972. The research design called for randomization of patients. Consequently, during the first 18 months of operation, 50 percent of the applicants did not receive services within the day hospital. Randomization ended in August, 1974, and the entire demonstration was concluded June 30, 1975. We did not request continuation funding but have continued since that time as an integral division of the Burke Rehabilitation Center and have just completed our fiftieth month as a day hospital.

SOURCES OF REFERRAL AND CATCHMENT AREA

Patients are referred from a variety of sources—Burke's own in-patient division, acute care and other rehabilitation hospitals, private physicians, community agencies, nursing homes, health professionals in the community, clergymen, family members and friends. The first patient was admitted to the program on March 27, 1973. Five hundred forty-eight patients admitted in the ensuing four years came from 150 different sources. The initial goal was to serve 40 patients per day. Currently the total patient census is 122 with an average daily attendance of 49 patients.

The catchment area served by the Day Hospital embraces southern and central Westchester County and parts of Northern Bronx County. The approximate size of the area is 132 square miles with a population of 788,736. About 12 percent of this population, or 92,058 individuals, are over 65 years of age.

CRITERIA FOR ELIGIBILITY

A patient is eligible for admission to the Day Hospital if he/she meets the following criteria:

(1) An adult who does not require 24-hour institutionalization but is not capable of full-time independent living because of chronic disease and/or physical impairment.

(2) One whose functional level can be improved through a regimen which includes medical surveillance, nursing services, and at least two of the following: occupational therapy, physical therapy, speech therapy, plus psychological counseling and socialization.

(3) One whose health care needs cannot be met solely in a physician's office, a hospital outpatient clinic, other ambulatory care settings or at home.

(4) One who is not confined to bed.

(5) One who does not exhibit disruptive behavior.

(6) One who is sufficiently oriented to time and place so that constant supervision is not necessary.

(7) One is currently under the care of a private physician or clinic.

(8) One who has medical insurance coverage or the financial resources to pay for Day Hospital care.

THE ADMISSION PROCESS

Those patients who, upon application, meet the criteria undergo a comprehensive evaluation by the Day Hospital's clinical team. An individualized health care plan is then developed. Central to the development of this health care plan is an assessment procedure that defines as precisely as possible the patient's medical problems, the nature of the disability, and the functional level in terms of capacity for self-care and mobility. The profile resulting from this assessment is used to determine the level of care to which the patient will be assigned. The care plan is submitted to the patient's personal physician for approval and/or modification. The patient's medical record includes all of the data collected during the admission process.

DISCHARGES

The Burke Day Hospital averages 11 admissions per month with an average of seven patients being discharged. As of May 31, 1977, five hundred forty-eight patients had been admitted. Of the five hundred forty-eight patients admitted, 426 had been discharged leaving a total census of 122 patients in the Day Hospital on that date. Of the 426 patients discharged, 58 percent had been in the Day Hospital for less than 60 treatment days. At the present time the average length of patient stay in the Day Hospital ranges from 50 to 60 treatment days, extended over a period of approximately six months.

CHARACTERISTICS OF PATIENTS

Patients now range in age from 30 to 93 years, with 33 percent under 60, 25 percent between 60 and 70, and the remaining 42 percent over 70. Forty-three percent are male and 57 percent are female. Fifty-three percent are single, widowed, separated or divorced; 47 percent are married.

The primary diagnostic categories include cardiovascular and cerebrovascular diseases, which account for 50 percent of the Day Hospital patients, with stroke and arteriosclerosis the major group. Twenty-four percent have diseases of the musculoskeletal system, eight percent suffer from fractures and other traumas, and six percent have miscellaneous primary diagnoses. The majority of the patients have other secondary illnesses.

The condition of all of the patients is dynamic rather than static—that is, ever changing. Consequently, different levels of care within the facility become most practical and economical.

LEVELS OF CARE

There are two levels of care in the Burke Day Hospital, *intensive* and *intermediate*, located on separate patient care floors in the building. The intensive level provides a concentrated, integrated package of therapeutic services on a one-to-one basis. As patients improve and reach the initial treatment goals, it becomes clear that the needs of some can be met in a less intensive program. In such instances, the patients are transferred to the intermediate level where they participate in a group therapy program with continued medical/nursing surveillance. The program at this level serves as a transition for the patients, preparing them for eventual discharge. For other patients, the continuing evaluation indicates that, in achieving their treatment goals, the patients have received the maximum possible day hospital benefit; if feasible, such patients are discharged directly home.

In all instances discharge planning carefully re-assesses the social support system and the environmental situation to which the patient is to be returned. The planning is carried out with family members and other social and health care agencies as needed.

HOURS OF ATTENDANCE

The hospital is open five days a week from 8:30 a.m. to 5 p.m. with the majority of patients attending from 9 a.m. to 3 p.m. or 10 a.m. to 4 p.m. The average Day Hospital patient is scheduled to attend two or three days a week. The average daily census is 89 percent of scheduled attendance.

RANGE AND SCOPE OF DAY CARE SERVICES

The range of services provided within our day hospital program include the following:

Medical services are provided by a half-time day hospital physician assisted by full-time nurse practitioners who constitute the liaison between the Day Hospital and the patient's physician. In addition to the Day Hospital physician, the panel of Burke's full-time medical staff are available on a consulting basis. These include internists, neurologists, and a psychiatrist. Ongoing consultation is available from psychiatrists at the New York Hospital-Westchester Division, which is located nearby and is also affiliated with Cornell Medical Center. This consultation is available for individual patients and also as part of our in-service education for staff.

This link also permits the transfer of patients to the psychiatric day hospital at the Westchester Division. In several instances we have achieved this transfer by having the patient spend part of the week with us and part at the psychiatric day hospital, with eventual attendance, when appropriate, at the psychiatric day hospital on a full-time basis.

Other medical services are provided by an ophthalmologist, otologist, and podiatrist. These specialists come to the Day Hospital on a regular basis. The other back-up services, mainly diagnostic in nature, are provided through the inpatient x-ray department and clinical laboratory. The orthotics/prosthetics department conduct evaluations and prescribe assistive devices as needed.

Nursing services, health care surveillance and personal care are a major part of our basic daily service to patients. Each patient is assigned to a primary care nurse who assumes responsibility for his total health surveillance.

Occupational therapy is functional and therapeutic in nature. It includes functional exercises, functional activities, activities of daily living, homemaking, perceptual training, communication and socialization, and specialized equipment. Therapeutic activity, which has a strong re-creative component, is prescribed and supervised by an occupational therapist. Individual and group sessions are included.

Physical therapy is provided through all the traditional modalities and included group as well as individual treatment. When a brace, or a change in bracing, is indicated, Brace Rounds and Bioengineering Services of Burke are available. Other inpatient back-up services include hydrotherapy, Hubbard tank and pool therapy.

Hearing and vision screening are integral parts of the initial evaluation. Speech therapy is provided for those patients requiring it, usually about one third of the patients. Audiological services are also available as needed.

The nutrition consultant provides nutritional assessment, instruction in the principles of good nutrition as needed, individual diet counseling, weight charts, and staff education in nutrition. She also consults with the food service manager on problems encountered.

Social Service includes casework services to patients and family members, orientation of new patients and family members, group counseling, and discharge planning.

Volunteers are carefully selected and are supervised by a designated team member. In many instances, these volunteers are older adults who have retired from their regular occupations and want to make meaningful use of their leisure time. One of the valuable services they provide is in speech therapy where, after training by staff, they conduct group sessions with patients as a reinforcement to the individual therapy provided by the speech clinician. These services include discussion groups, writing clinics, word-finding exercises, and role playing. Another example of volunteer services is the retired social worker who assists with discharge planning by taking a patient to visit and evaluate the potential of a local senior center.

Transportation is the essential ingredient for connecting patients with the Day Hospital services. Managing transportation presents the single greatest challenge, the greatest frustration, and the largest single expense. Although some patients are transported by family members, most of them come by wheelchair van, provided by a commercial vendor.

PHYSICAL FACILITIES

The Day Hospital occupies part of a 3-story building which formerly served as an inpatient facility. Part of the first floor and the entire second floor are devoted to patient treatment, with the third floor being used for administrative offices. These floors are connected by an elevator and stairs. In toto, the Day Hospital occupies about 12,000 square feet of space.

STAFFING

This is multidisciplinary, using a team approach combining professionals and paraprofessionals. The team is made up of a physician, a clinical specialist in nursing, primary or family nurse practitioners, nurses, physical therapists, occupational therapists, social workers, speech pathologists, patient activities specialists, nursing assistants, and a nutrition consultant.

The treatment approach is an integrated one. For example, speech therapy goals for a patient are clearly spelled out for other staff who will be working with that patient. By reinforcing the speech pathologist's efforts, the staff produce a cumulative impact that is quite effective in improving and/or restoring the patient's speech and ability to communicate.

Volunteers work hand in hand with various clinical team members in caring for patients.

Burke Rehabilitation Center, the parent institution, through its medical, clinical, and technological staff, provides back-up medical and rehabilitation services for the Day Hospital.

FINANCING DAY HOSPITAL TREATMENT

One of our initial goals was to develop and uncover payment mechanisms for this new health care option. As a division of a Medicare-approved hospital, the Day Hospital is eligible for reimbursement under Medicare-Part B, classified as "outpatient services." However, Medicare does not currently cover some of the most essential services—viz., transportation, social services, pre-admission assessment, midday meal, and recreation therapy. The current distribution of reimbursement mechanisms for patients is as follows:

79 percent partially reimbursed by Medicare-Part B, with the co-insurance amount being paid either by Medicaid, by a private insurance policy or by the patients.

9 percent are Medicaid-eligible, and the Day Hospital is reimbursed on a per diem rate by the Department of Social Services. In New York State, medically-oriented day care/day hospital services are recognized as a health care option. The State Health Department sets the rate, and the Department of Social Services determines eligibility and authorized the reimbursement.

7 percent are reimbursed by a major medical insurance policy which ranges from 80 percent to 100 percent coverage, depending upon the carrier.

5 percent of the patients are "self-pay" with either the patient or a responsible relative paying the entire amount.

It is difficult to make cost comparisons of day hospital care because it is not possible to assign price tags to the human cost factors. Many of the services provided are not necessarily available elsewhere in the community. Consequently, there is no equitable basis for comparison with a similar set of services. For example, some Day Hospital patients could be maintained at home through home health services such as nursing, physical therapy, occupational therapy, speech therapy and home health aids. Within Westchester County, if those services were provided by a private or public home health agency in the course of one day, the cost to third party payors would be one and one-half times as much as it is in the Day Hospital, without providing physician services, midday meal, socialization and escape from isolation, and relief from patient management for family members. However, for the patient who is essentially homebound and who could not tolerate the trip to the day hospital, the same home health service package is the obvious solution.

EDUCATION AND TRAINING

Students: Graduate students carry out their clinical practice in social work, nursing and speech pathology; medical fellows from Cornell Medical College serve at the Day Hospital during the summer. In addition, students in occupa-

tional and physical therapy and psychology have fulfilled field work as volunteer placements.

Staff: The Day Hospital has in-service education and training for all staff. In addition there are training programs for non-professional staff under On-Job-Training contracts with the Department of Labor and the Association of Rehabilitation Facilities.

Other education and training efforts: Since initiating our program four years ago, we have had more than 1800 inquiries by mail and telephone from communities eager to initiate similar services and hoping to learn from our experience. DHEW was helpful in working with us on a film, "Home for Supper," which describes the program in 11 minutes and is useful for orientation of community groups. An updated version was filmed one year later and has been shown throughout the United States and abroad. However, administrators and health professionals require more detail than the film permits, and we have tried to meet their needs by sponsoring periodic Day Hospital Symposia at Burke with the entire Day Hospital staff and some patients participating. This program is self-supporting. We have also provided one-day consultations on a fee-for-service basis. In all, we have provided this type of training to 100 different communities in the United States and Canada.

In May, 1977 we organized and conducted a Burke Day Hospital Traveling Seminar to the United Kingdom, where 27 professionals from various parts of the United States visited 11 different types of day hospital, day centre, geriatric inpatient and health center programs with lectures by leading geriatricians in England and Scotland. The tour was arranged on a self-supporting basis, and credit was awarded by the New York State and California Board of Nursing Home Examiners. It provided an opportunity for participants to exchange ideas and experiences en route and to gain new insights by visiting programs that have been established much longer than ours. This was done in cooperation with consulting geriatricians at the University of Glasgow, as an outcome of the Burke Day Hospital's having sponsored a Visiting Cornell Professor in Geriatrics at the Day Hospital for a four-month period in 1976. During that period we provided education and training programs in geriatrics for nursing personnel and for Cornell University medical students. During the past year the first endowed professorship of geriatric medicine at an American medical school was initiated at Cornell Medical College. During the coming year the Burke Day Hospital will be an elective for Cornell medical students in the Department of Community Medicine.

In the course of four years, papers have been presented by Burke Day Hospital staff at national conferences of the American Nurses Association, American Psychological Association, American Public Health Association, American Speech and Hearing Association, American Congress of Rehabilitation Medicine, American Geriatric Society and the Gerontological Society. We are currently working on a Day Hospital Handbook, a Day Hospital Speech and Hearing Manual and a Patient Activities Manual wherein we will publish materials designed specifically for use with day hospital patients.

BURKE'S FUTURE PLANS

Burke Rehabilitation Center was privileged to be the site of the first day hospital demonstration project funded by the Department of Health, Education and Welfare. Burke's Board of Directors has demonstrated its commitment to continuing this health care service by its ongoing support of the program, and it is currently planning the construction of a purpose-built day hospital which will provide four different levels of care within the one institution. The four levels of care will include a unit for intensive rehabilitation, one unit for medically-oriented day care at a less intensive level, one unit as a social day center for those persons whose impaired physical functioning denies them access to senior centers for the more physically fit, and a fourth unit for the psycho-geriatric patient whose impaired mental functioning requires daytime supervision, socialization and reality orientation without 24-hour institutionalization. An important part of the program will be a comprehensive assessment and intake unit to determine the appropriate level of services needed by an applicant.

Planned in conjunction with this day hospital program is a demonstration program in supportive housing for the disabled. Such housing, another unmet need in our community, calls for the development of services that will become part of the same continuum of community health care.

CONCLUSIONS AND RECOMMENDATIONS

Community network of services needed.—The Burke Day Hospital experience points up the need for a community network of services for the geriatric population. The following should be included: a centralized geriatric assessment service, inpatient and outpatient health care services, a day hospital for the physically disabled, a day hospital for psycho-geriatric patients, a medically-oriented day care center, multi-purpose day centers for the disabled as well as for the physically able, and, finally, supportive housing for those who are semi-independent. We believe a comprehensive service system of this kind would permit the individual services to be utilized by patients and families in the most effective and economical way.

Financing program development.—Adequate, broad-based financing is needed in order to stimulate communities in developing comprehensive programs and to discourage the proliferation of fragmented services currently responsive to fragmented sources of funding. Physical, social, and emotional factors in the older person's health or illness are not separable. Treatment, therefore, should consider all those factors and integrate them, and financing policies should support such a program.

The development of effective non-institutional services should be assisted and encouraged in existing health care facilities and community service agencies that have already demonstrated their experience, expertise and commitment to serving those affected by chronic disease and disability.

Training of health professionals and paraprofessionals.—Training opportunities should be made available to physicians, health professionals and paraprofessionals for the purpose of increasing their awareness and skills in adult day care and treatment.

Policy-making and research evaluation efforts.—In the United States, experience in adult day hospitals and medically-oriented day care is recent and limited. Our first-hand exposure to one-day evaluation surveys, telephone reviews, etc. has demonstrated clearly the extravagance, the inaccuracy and the injustice of comparing the cost of one type of care with another which is totally or partially dissimilar, of a different level of quality, and in a totally different setting. Such surveys are usually conducted by one or more professionals who are knowledgeable in health care but who should not be making one-day, and therefore hasty, judgments of a mode of health care with which they are not familiar. The tendency is to translate combined observations into a numerical score which is computer- or assessment instrument-oriented but which is totally incapable of capturing the quality of the services rendered and their impact upon the recipient. And, unfortunately, available assessment instruments are limited in their capacity to measure the minimal gains in this high risk population. The result of such surveys may be the victimization of the chronically ill, disabled elderly who will eventually be subject to the policies that flow from such evaluations. It is our recommendation that future demonstration efforts provide the opportunity to test a community network of services to determine how, for whom, and to what degree such services would be effective. In the evaluation process, the service providers should participate in helping the evaluators develop a realistic, effective evaluation plan.

ITEM 8. STATEMENT OF LOUISE WOERNER, VICE PRESIDENT,
J. A. REYES ASSOCIATES, INC., WASHINGTON, D.C.

Mr. Chairman, it's my pleasure to report to the Committee a project of the Community Services Administration (CSA) which is successfully demonstrating a model delivery system which can enable the elderly rural poor to remain in their homes, as long as they do not develop severe health problems. CSA contracted with our firm, J. A. Reyes Associates, Inc., (JAR) a minority owned research firm, which originally designed and proposed the model to test the concept for potential replication and program planning purposes. The contract is under the direction of the Chief of the Older Persons' Program of CSA. It is called Project EXITO (Success in Spanish).

BACKGROUND

As you recall, the Economic Opportunity Act of 1964 cites the need for programs for the elderly poor, calling for ". . . such investigations and studies, including consultations with appropriate agencies and organizations, as may be necessary to develop and carry out a plan for the participation of the elderly in

programs . . . providing employment opportunities, public service opportunities, education and other services and activities which assist the elderly poor to achieve self-sufficiency" (Title 1, Part A, 42 U.S.C., 2950; Sec. 610). In dealing with urban and rural community action programs, this same act calls for ". . . the maximum feasible participation of residents of the areas and members of the groups served", so as to "assure that those programs and projects are otherwise meaningful to and widely utilized by intended beneficiaries. . . ."

In addition, the most recent amendment to the Older Americans Act (1975) in dealing with Model Project Requirements also recognized that needs of low income minority elderly are not being met and urged emphasis on the "needs of those 'not receiving adequate services under other provisions' of the Act, with emphasis on low income minorities and the rural elderly" (Select Committee on Aging, 1975).

Both legislative statements recognize:

- The need for alternatives to institutionalization among the elderly, and
- That there are special needs among poor, rural and minority elderly which must be met.

The need to deal with these problems has been acknowledged, with the Community Services Administration having a definite charge in minority elderly. Unfortunately, most contracts awarded by the Administration on Aging (AOA) and the U.S. Department of Health, Education and Welfare are to analyze or further define or describe problems such as:

- Underutilization of services by minority elderly, and
- Impacts of cultural differences, socio-economic status, language barriers and access to services.

However, most community service groups and many sociologists say we must view such research and data available on minority elderly with increasing uncertainty, because of the highly ethnocentric orientation that pervades this research.

For example, Studies of Mexican-Americans generally fail to have an aggressive posture vis-a-vis the dominant [Anglo] culture. Instead, the perspective is largely ethnographic which finds within Mexican-American society and culture the sources of existing deficiencies in services utilization and economic development. Torres-Gil, at Brandeis University, one of three national coordinators of The National Advocacy Association for the Spanish-Speaking Aging, argues that the American system should begin to make concessions to Hispanic American culture rather than to expect acculturation on the part of Hispanos in order to bring better utilization of social services. CSA, therefore, determined to demonstrate that a cost effective delivery system could be developed to provide services needed to enable rural elderly poor to remain in their homes. Our firm had proposed a model, which we were contracted to test in rural South Texas, with the target population of elderly rural poor. Most are Mexican-Americans.

The town selected was Natalia, Tex., 40 miles Southwest of San Antonio, Tex. The population is about 1,300. Natalia is in the Alamo Area Planning Region (A2) which includes twelve counties in and around San Antonio, Tex. In 1970, the Texas Governor's Committee on Aging estimated that 28 percent of the over 60 population of this area are Spanish-speaking.

Across South Texas Mexican-Americans make up 64.2 percent of all the persons 60 years and older who are below the poverty level. (Texas Governor's Council on Aging, 1970). This population of Spanish-speaking have special problems which have not been successfully met by other programs. This, therefore, seemed an excellent test for our model.

Persons with low income in general underutilize services that are available to them, although they are unable to pay for private care and treatment. Among the Spanish-speaking minority, where low income prevails as a general rule, these problems are compounded by cultural factors. For example, the breakup of the traditional extended family among Mexican-Americans has left many elderly without a means of support that was expected in the past. This situation becomes especially severe because elderly Mexican-Americans may not know of available services because they were previously uncovered. Many were previously ineligible for Social Security, for example, because they were farm workers who didn't receive Social Security until 1957.

We have found in our previous work with minority poor that programs that serve multiple aged populations, for example Food Stamps, provide limited services to elderly poor. Persons of limited education and limited English speaking ability are at a distinct disadvantage when they must apply for services

through our bureaucratic process. We anticipated this problem in our test of Project EXITO. Equally cogent is the fact that past discrimination has fostered a cynical attitude among the Spanish-speaking elderly. This furthers the underutilization of traditional services. As a result, there are many older Spanish-speaking persons who either cannot or will not avail themselves of services that they need.

Delivery of services to any poor elderly ethnic groups in a rural setting involve special problems. These problems require special solutions, particularly in the case of low income and minority elderly. Current programs that exist for the elderly, such as Meals-on-Wheels, congregate eating, and the provision of transportation to help with errands or health needs, may be effective in urban communities. In a rural setting, they are exceedingly cumbersome and expensive.

Limited financial resources is the critical problem in the provision of services to elderly living in rural areas which are large geographically but small in population to be served. The government often allocates money as a function of the number of people to be served. Under this dollar allocation method, rural areas are often disadvantaged because the establishment of systems for the delivery of services is not cost-effective in terms of the number of people to be served. The resolution of this basic problem is the focus of CSA's Project EXITO.

Consolidation of programs between towns and counties is a means by which services have been provided by DHEW in rural areas. The problem with this is that there is a need to rigidly schedule the provision of services to insure that all eligible people are given the opportunity to take advantage of them.

However, while it is reasonable to schedule services, it is impossible and unreasonable to expect elderly to schedule their needs. For example, the availability of transportation once a week at a specific time does not serve the unpredictable medical needs of an elderly person. It is imperative, consequently, that there be flexibility in the provision of services to elderly. Yet there is little likelihood that government agencies will ever have sufficient funds to allocate to every small town the amount of money necessary to foster this flexibility. Moreover, there has been a tendency to initiate programs that were designed for the general population whose objectives were markedly different from those of the minority elderly. To overcome this sense of skepticism, it is necessary to shape programs for the minority elderly by using a cultural orientation. CSA has gone far to correct this situation by the use of indigenous persons as contact or outreach workers. Nevertheless, extensive social innovation is needed to improve the delivery of services to the elderly poor and minority elderly, most particularly in rural America.

The difficulties that aging imposes on a person tend to be even more severe among poor elderly Hispanic Americans than among Anglo-Americans. This situation has been described as one of double jeopardy, for not only are the poor Spanish-speaking elderly disadvantaged by problems that plague all aging persons, but they also face the inherent difficulties of a group that is outside the mainstream of American culture.

In summary, the problem to which Project EXITO has addressed itself is the need to find a cost-beneficial alternative to institutionalization that could:

- Flexibly provide services in a rural area.
- Effectively account for the special needs of the Hispanic elderly poor, and
- Successfully enroll the target population as participants.

As we began Project EXITO we canvassed the community's 334 homes to discuss problems. We found the Mexican-American elderly in Natalia consider transportation, health and income as very serious problems, whereas fewer of the Anglo elderly we talked with found the same problem to be very serious.

Other problems that resident Mexican-American elderly said are very serious are: housing, loneliness, limited education, lack of friends and not feeling needed.

This canvass proved that the perceived needs of elderly in Natalia are similar to those identified by elderly who participated in surveys conducted by North Texas State University and Lou Harris for the National Council on Aging. This established the basis for replication, of the model or generalization of our approach to legislative proposals for CSA and DHEW programs.

CONCEPTION OF EXITO

JAR hypothesized that the mobilization of community resources, which is the CSA approach to problem solving for the poor, could meet the special needs of the rural Hispanic elderly in achieving self-sufficiency. It was our belief that there are people available in every community with skills necessary to service

the needs of the elderly. We further proposed that elderly have skills which could be tapped to the benefit of the community. We, therefore, thought that if we could foster a sense of community spirit, we could act as a catalyst to the mutual aid of neighbors. The mobilization of resources within the community would provide the flexibility necessary for the delivery of services to this rural and hard to enroll target populace.

The exchange of services was an integral element in our conceptualization of Project EXITO. Self-respect and pride are key considerations in the willingness of Spanish-speaking elderly poor to utilize services. To accept welfare is to diminish one's self-respect, in the eyes of this population, and the provision of social services by the government is often regarded as a form of welfare. By exchanging services, the elderly became part of a mutually beneficial relationship within the community. They can maintain their pride while accepting services because they can increase their sense of self-worth by helping others.

A premise of our study is that among the Mexican-American elderly, there exist a great tendency toward intergenerational interactions and supportive friendship relations. The concept of an intergenerational exchange of services, on which EXITO is based, directly tied into this cultural norm by hypothesizing that the mutual aid to be mobilized within a community could simulate the support of the family on which the elderly previously relied. Consequently, the conceptual basis of Project EXITO has its roots in a cultural norm of the Hispanic population.

DEVELOPMENT AND IMPLEMENTATION OF THE MODEL

It is not unique in a community that neighbors help each other. However, the absence of a structure makes difficult provision of services to all who need it. The formalization of this concept as a service delivery system requires the development of certain key components. One is a means to identify people who need help. Second is the formation of a pool of people who are willing to provide services. Lastly is an administrative mechanism to coordinate the two groups in a timely and reliable fashion. Because of the research and demonstrative nature of Project EXITO, additional components were necessary. The evaluation of the project as a cost beneficial alternative to other models required a means to weigh the relative values of the services and a system to record participation data.

A determination of the value of different services is a key ingredient in the design of a cost/benefit model. JAR feels that a societal or work-related model is appropriate for this end. In this prototype, the actual market value or an arbitrary value approximating the market value is attached to a particular service. In addition to the work-related model, JAR is using a human value model to ensure the free exchange of services and to retain the dignity of each individual's self-worth. Here, all adult time is priced equally. Exchanges, therefore, are facilitated on a direct one-service-for-another basis.

PRELIMINARY RESULTS

By May 31, 1977, only five months of operation, we think the results of Project EXITO have demonstrated the model to be the most cost-effective and dramatic seen in any Agency program to date. Most residents of Natalia have participated in the program. The services exchanged within the framework of EXITO include:

Transportation,	Shopping,
Cooking,	Cleaning,
Companionship,	Haircuts,
Escort,	Babysitting.
Translation,	

Other services available include:

Bathing,	Gardening,
Carpentry,	Sewing,
Crafts,	Nursing aide,
Reading,	Painting,
Home repair,	Plumbing.
Counseling,	

These are provided without cost. Only administrative cost must be paid. This model is therefore more cost effective as well as more efficient and timely than presently used programs of transportation, or home health care. One interesting personal example is that an 80 year old blind man, who was very discouraged and

likely to become institutionalized, was asked to tell stories about Indians to children. As a result the children often stop by to visit as do their parents. This has resulted in a significant improved quality of life for all involved.

The on-site director of EXITO has served as an information and referral source for a number of elderly in Natalia in regards to various government programs which has increased the receipt of entitlement by this group.

Ancillary effects of Project EXITO cannot be compiled in statistical form. Townspeople have formed other groups. Thus Project EXITO has become a focus of community resource mobilization through which different groups find the people to sustain their activities. One example was the organization of a Natalia Chamber of Commerce. Town leaders will use this community organization to secure additional Federal and State money. According to the Mayor of Natalia, EXITO was the catalyst to that action. Through EXITO and the Chamber of Commerce a Senior Center where townspeople can congregate and enjoy inter-generational interaction has been set up. The American Legion leased their Hall, which was not being used, for 5 years at \$1 a year to the newly formed chamber. CSA Community agency donated funds and paint to refurbish the building. The EXITO group did the work.

Finally, EXITO has formalized the local support by establishing a citizen's advisory committee of fifteen residents of Natalia. Of the fifteen, twelve are below the poverty guideline and nine are Spanish-speaking. Of those nine, three are 60 years or older. The committee has taken many initiatives including organizing group recreational activities, such as a community covered dish luncheon where two elderly fiddlers played and eighth graders did musical skits. One elderly citizen who had not been out of her home in several months before someone took her to this luncheon commented on the EXITO program saying, "Natalia used to be dead until EXITO came."

The concept of a services exchange is particularly appropriate to the needs of the Spanish-speaking elderly. Through the use of such an exchange, older persons became part of a mutually beneficial relationship within the community. They are able to maintain their pride while accepting needed services because they are providing help for others. They can see themselves as valuable members of society. And the inter-generational exchange of services on a mutual aid basis can serve to simulate the support of family upon which elderly Hispanic persons have traditionally relied. The special needs of the Spanish-speaking elderly in the rural community of Natalia can be met cost effectively, by Project EXITO. This model in which the elderly will be able to live independently, outside of an institution, and still receive needed services can be replicated or used as a model for other program designs, greatly increasing older persons services at very minimal costs.

The intergenerational spirit of self-worth traditional to elderly persons who as emeritus members of our society prefer to be self sufficient can be retained despite the breakdown of the extended family. In the EXITO model the low income educational level and limited language skills of Spanish-American elderly will be minimized in their limiting effects upon access to services because of the exchange nature of the program. And the community orientation central to Project EXITO will help to circumvent communication barriers stemming from language and racial difficulties that are inherent within traditional service delivery programs for minority poor. Traditional programs to date have failed to meet prescribed goals. Innovative efforts such as Project EXITO are crucial if the needs of poor, rural, elderly minorities are to be served effectively.

Appendix 3

CHARTS: ELIGIBILITY FOR "ALTERNATIVES" IN FOUR FEDERAL PROGRAMS

**"ALTERNATIVES" AND THE
OLDER AMERICANS ACT
AREA PLANNING AND SOCIAL SERVICES***

Eligibility

For older Americans, but no specific age limitation and no income limitation

Services covered

Authorizes funding for in-home, long-term care services as part of local service system for older persons. No Federal limitations on services to be provided, but 1975 Amendments made home services a priority, including homemaker, home health, shopping, escort, reader, letter-writing, and other services.

Administering Agency

HEW, OHD, Administration on Aging

NUTRITION PROGRAM FOR THE ELDERLY**

Eligibility

Age 60 or spouse, no income limitation

Services Covered

Authorizes low cost, nutritious meals in congregated centers to promote better health and reduce isolation.

Home delivered meals also authorized; 13% of all meals served were home delivered in Fiscal Year 1976.

* Title III, Older Americans Act

** Title VII, Older Americans Act

"ALTERNATIVES" AND SOCIAL SERVICES GRANTS TO STATES

*Eligibility**

Varies by State

Aged SSI recipient and all ages with income below 80% of State median income can be served without charge

May be a service charge for those with incomes between 80% and 115% of State median income

*Services Covered**

Varies by State

Can Include: Homemaker Services
Home Management and Maintenance
Day Care
Home Delivered Meals
Health Support Services (NO Medical Services)
Services to Adults in Foster Care

Definitions

No specific service definitions set by statute or regulation, but states must show that services provided meet one or more of 5 goals set by statute.

Administering Agency

Present: HEW, Office of Human Development

Pre-Reorganization: HEW, Social and Rehabilitation Services

*Eligibility and services covered determined by State and must be approved in State Annual Social Services Plan.

Social Security Act, Title XX

MEDICARE AND HOME HEALTH CARE

Eligibility

Aged and long-term disabled

No income limitation

Physician ordered skilled nursing or physical or speech therapy

Services Covered

Under Part A: 100 home health visits after three-day hospital stay, full cost paid

Under Part B: 100 home health visits without prior hospitalization, deductible must be met

Definitions

Home Health: Part-time skilled nursing care
Physical, occupational, or speech therapy
Medical social services
Medical supplies and equipment
Part-time home health aides

Home Health Agency: Public or private organization primarily engaged in providing skilled nursing and other therapeutic services. Must be Medicare-certified.

Administering Agency

Present: HEW, Health Care Financing Administration

Pre-Reorganization: HEW, SSA, Bureau of Health Insurance

Social Security Act, Title XVIII

MEDICAID AND IN-HOME SERVICES

*Eligibility**

Aged, blind, disabled, or AFDC recipient

Low income

*Services Covered**

Part-time skilled nursing care from home health agency

Part-time RN or LPN under physician supervision

Part-time home health aides from home health agency

Medical supplies and equipment

Physical, occupational, speech, and audiological therapy from home health agency

Personal home care

Definitions

Home Health: Regulations require States to provide minimum of nursing, home health aide, and medical supplies and equipment services

Home Health Agency: Regulations define as public or private agency qualified to participate under Medicare

Administering Agency

Present: HEW, Health Care Financing Administration

Pre-Reorganization: HEW, SRS, Medical Services Administration

*Eligibility, number of visits allowed, and services covered varies by State.

Social Security Act, Title XIX