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:
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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.
Part 6. Holyoke, Mass., October 12, 1977.
Part 7. Tallahassee, Fla., November 23, 1977.
(Additional hearings anticipated but not scheduled at time of this printing.)

CONTENTS

HEALTH CARE FOR OLDER AMERICANS: THE "ALTERNATIVES" ISSUE

WEDNESDAY, NOVEMBER 23, 1977

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Tallahassee, Fla.

The committee met at 9:15 a.m., pursuant to notice, in the Georgia Bell Dickenson Housing Center, Hon. Lawton Chiles presiding.

Present: Senator Chiles.

Also present: William E. Oriol, staff director; Kathleen M. Deignan, professional staff member; David A. Rust, minority professional staff member; Thomas D. Woodbery, legislative assistant to Senator Chiles; Boley Johnson, district representative for Senator Chiles; and Patricia G. Oriol, chief clerk.

OPENING STATEMENT BY SENATOR LAWTON CHILES, PRESIDING

Senator CHILES. Good morning. Today, the U.S. Senate Committee on Aging resumes its hearings on community health and long-term care for all older Americans.

The committee has already conducted hearings in Washington, but I consider it important for the committee to come to Florida, the State with the highest proportion of elderly in the Nation. Florida's experience and plans in developing community options for long-term care will be, I think, of great value to the committee as we develop legislation and look to the future.

I think it is also appropriate that we should have the hearing in this building, which has served so well as a housing alternative. I thank our hosts for making this space available to us today.

I am deeply concerned about Federal long-term care policies and how they make it difficult for State and local governments to develop effective programs to care for frail and handicapped older Americans.

We found contradictions in policy from one Federal agency to another. We found real shortcomings in vision. We talked to people who tried to develop adequate home health and home help services. They struggled to build programs of adult day care or provide housing with adequate services, but they encountered almost insurmountable obstacles, and generally those came from the Government.

The Department of Housing and Urban Development told a woman in California that she could not, under existing regulations, include a center for health services in an apartment building for the elderly because it would be a "major commercial facility."

We also found there was no one within the Department of Health, Education, and Welfare with responsibility for the development of a long-term care policy.

Administration Response

We have made some progress. At my urging, the Department recently gave the committee assurances that they will place a very high priority on improving the delivery of long-term care services. They have also consolidated responsibility for policy development in services which support independent living among the chronically ill or disabled.

I consider these actions a major breakthrough, but we are still far from a national policy to encourage this development.

Quite often, the real initiative is being taken by the States. I am not surprised at that. That has always been so. It has always been a part of our system, and I think it is good, but I think if we could have the Federal Government see a little quicker the good that is going on in the States, that would help much more.

I am concerned whether Federal policymakers will learn from these initiatives. We are experimenting and demonstrating all over the Nation, but are we going to find a way to share and learn from these valuable experiences?

That is why we have come to Florida. There is much experience here, and we came to hear you give us those experiences.

Some witnesses will describe the initiatives taken under Florida's Community Care for the Elderly Act, which authorized demonstrations in home delivered and family placement services, multiservice centers, and adult day care.

We will also hear from persons who are concerned about the future care in nursing homes. Most experts agree that we must make a commitment to community alternatives to institutional health care for the elderly. However, we must not forget that many people will need the kind of intensive care that can only be provided in a nursing home setting. As important as the development of alternatives is, we cannot ignore the improvements which must be made in our Nation's institutional health care.

I believe that we have now achieved an awareness of the needs and some momentum in developing solutions, but we can't stop where we are. Major decisions still must be made not only on what the Federal role in this development will be, but also on what the most appropriate services should be.

It seems, over the years, that when you get to the point where you have to make a tough decision, the easiest thing is to study it and put it out on the pile. I think this is one area that we have studied and studied, and piloted and piloted, and now we have to look at some of the results we have, and say we are going to embark on a program, and we are going to try to quit determining if it is going to save money or cost more money if we decide. I think we really have decided, or we should decide, that these alternative forms of care are necessary for relieving the pressure of having to build more and more nursing homes and other complete institutionalized care. If this is the only humane thing to do, to allow the elderly to not have to be institutionalized for as long as possible, then I think the time has come for us to go forward with these commitments.

We are delighted to have the opening panel on community care for the elderly and to have Representative Rish, who has been taking a leadership role in this area. We also expect to have other people here.

Mr. Lipscomb is here as the staff director of the aging and adult services program office from the Florida Department of Health and Rehabilitative Services. We think we will have a couple of other members come in. We will start with you, Mr. Lipscomb, and let you proceed.

PANEL ON COMMUNITY CARE FOR THE ELDERLY

STATEMENT OF E. BENTLEY LIPSCOMB, TALLAHASSEE, FLA., PROGRAM STAFF DIRECTOR, FLORIDA OFFICE ON AGING AND ADULT SERVICES

Mr. LIPSCOMB. Thank you, Senator Chiles.

We appreciate the opportunity to be here today as you continue to receive testimony on "Health Care for Older Americans: The 'Alternatives' Issue." The Florida Office on Aging and Adult Services is vitally concerned with this issue, which affects so many older Floridians presently, and will impinge on the lives of countless others in the future.

With the advent of medicare in 1965, the Federal Government increased the financial means with which elderly were able to obtain institution and home-based, skilled nursing care, oftentimes referred to as long-term care, despite the programmatic limitations which you mentioned, which make it anything but long-term care. Medicare fostered the development of ostensibly less costly and more appropriate services than those of acute care in a hospital, but similar to other health care costs, the costs of long-term care have increased dramatically from $250 million in 1967 to $15.5 billion in 1976.

Now as in 1965, we are seeking less costly and more appropriate alternatives to long-term care, only now we are seeking alternatives to what was then the solution. With costs of institutional long-term care comprising by far the largest portion of our total health care dollar and 98 percent of the medicare reimbursed long-term care, we have finally begun to seriously seek community, home-based homemaker, chore services, day care, and nutrition programs, based on a belief that noninstitutional alternatives which address the difference between the client needs and provider capabilities will be more economical in the long run.

The cost of services is not the only problem in health care for the elderly. The health service needs of the elderly are primarily in the areas of chronic disease, rehabilitation, long-term care, home health care, and preventive medicine. However, these are the areas in which the present American health care system is the weakest. The system is oriented toward treatment of acute illness rather than long-term.

This situation is reflected in and reinforced by current medicare and medicaid programs which encourage institutionalization by providing the greatest coverage for institutional care. There is at the present time no coordinated approach that can give older persons the care necessary to prevent serious illness and to maintain and improve their health.

Many Elements In Place

Many communities have the elements of a coordinated health care system—medical personnel, hospitals, nursing homes, day care center, clinics, screening programs, home delivered meals, and transportation. These are some of the things necessary for appropriate care. Nor are medical services adequately coordinated with vital supportive social activities. As a result, many older persons are institutionalized because no other alternative exists and many others go without necessary care.

I would add, parenthetically, that another thing that is beginning to disturb me greatly is that there is little or no coverage for the person who finds himself older in the American society today and is not poverty stricken, that people who have taken care of themselves all their lives, have accumulated funds, are able to purchase and seek out care in other instances. Federal programs basically take care of the poverty group, but the large mass of people in the middle find themselves looking for resources which in many cases do not exist.

Contrary to popular belief, most people do not live in institutions. In fact, on a national average, only a small percentage are in nursing homes, which often results from factors other than mental or physical conditions. Generally, 10 to 20 percent are recovering from a recent acute illness and will stay in the nursing home until their condition improves enough to allow them to care for themselves, which is usually less than 3 months.

However, for 80 to 90 percent of the patient population, the nursing home provides a residential setting with some medical services. For many of these patients, it was a need for personal care rather than for medical care, which led to their admission to the nursing home. One recent study of nursing home patients in another State concluded that only 37 percent needed skilled care, another 26 percent needed minimally supervised living arrangements, 23 percent could manage at home with periodic home visits by a nurse, and 14 percent needed no care or supervision at all, but were simply being kept in the facility.

For a smaller number of older persons—it is imperative because of the level of care needed, and for these persons quality must be assured. However, the nursing home should be viewed only as one of the many alternatives in a coordinated continuum of services. According to statistics, 25 percent have a chance of being institutionalized before death. Persons most likely to be institutionalized were identified primarily as those who were socially isolated to some degree, those living alone, those without a spouse, and those with few children, and women. In the State of Florida, we have a particularly acute problem in that many people move here from other States and leave their extended family behind, either in the North or the Midwest, and when a tragedy befalls them here, they are more likely to be institutionalized than possibly in other sections of the country, where they would be in close proximity to family.

Florida Community Care Program

I would like to address and emphasize the State of Florida program, which we call community care for the elderly. The basis for this pro-

gram is a continuum of care. By coordinating a broad range of services which we identify as preventive, the elderly are able to stay in their own homes as long as possible. When physical, emotional, or social incapacity begins, interventive services can be instituted to maintain independence and dignity. Examples of preventive services are telephone reassurances, health maintenance, counseling, transportation, and leisure services.

Home delivered meals, homemaker, home health care, adult day care, family placement, adult foster home placement, and adult congregate living facilities placement are some services which we consider to be interventive.

Florida has, as you have mentioned earlier, the fourth highest elderly population in the United States, and the highest ratio of elderly to total State population. Dade County alone has more people over 60 years of age than do 16 other States combined. Hillsborough and Pinellas Counties have more senior citizens than do 21 other States combined. By 1979, the elderly population in Florida is projected to increase to over 2 million.

Problems facing many of our elderly include fixed incomes, limited mobility, frailty, poverty, lack of transportation, mental health problems, nutritional inadequacies, chronic illnesses, isolation, and so forth. Those elderly who are most likely to need specialized services are as follows, and these are based on present statistics:

Presently we have people 75 years of age or older amounting to 506,046 Floridains; single or widowed women living alone, 376,039; minority aged, 152,451; and rural elderly, 147,159.

As of July 1975, approximately 30,000 aged Floridians were residing in institutions such as nursing homes or mental hospitals. An estimated 16 to 30 percent of those persons could have remained in the community if home or community services had been available to them, or if the family placement program, which we anticipated beginning in January, were operating at that time. The heavy utilization of nursing homes is attributed to the lack of community services available to impaired elderly persons who have difficulty attending to their daily needs without assistance. Some families lack financial resources and support services to care for and support elderly relatives in their homes.

In Florida, an estimated 229,366 to 305,821 elderly persons—12 to 16 percent—are functionally impaired. Based on national statistics, a conservative estimate of 34.2 percent of those persons currently receiving home delivered services would otherwise require institutionalization.

The unmet need for the three statewide core community care services—home health, homemaker, and home delivered meals—is between 4 and 6 percent of the noninstitutionalized elderly.

I will give you some other statistics to go into the record, but let me just say we have begun new pilot community care programs in six areas in the State of Florida. They are not as yet full blown, and they are not generalized to the entire State. We are hoping, with the availability of funding, to do this in the near future, but we feel that it is crucial to institute community care statewide. I don't want to give you the notion that these services are in place in all of the counties in Florida at this time.

76,000 TO 115,000 WITHOUT ACCESS

These figures translate to between 76,455 and 114,683 people who need but do not have access to homemaker services, personal home health services, and/or home delivered meals. The demand for these services, based on a survey, does not include the number of institutionalized older persons who could return to their communities if these services were available.

The elderly become ill with greater frequency than younger persons, and when they become ill, their illness is of longer duration. Although people 65 years of age or older comprise approximately 10 percent of the total population, they account for 30 percent of health care costs. Many of their special needs are a result of an acute or chronic illness which limits their mobility and decreases independence. Approximately one-third of the elderly who need home-delivered services have conditions which require continuing care; the remaining two-thirds have short-term needs resulting from an illness or personal crisis.

When illness strikes, homebound elderly must rely on friends, family, or home-delivered services for subsistence. Between 1970 and 1975, the number of field visits by the health department decreased from 500,000 to 350,000. The emphasis for this period of time was on the clinic service program. Increased field visits, as a core public health service, is recognized in the next budget period. At the present time, the department is evaluating the purchase of home health care from profitmaking organizations.

Inflation has eroded the purchasing power of persons on fixed incomes. Rising unemployment has reduced job opportunities for elderly workers. For persons on fixed incomes, it is increasingly difficult to absorb the cost of providing for their own medical and social service needs. According to the 1976 University of Florida statistical abstract, in 1969, the per capita annual income distribution for the elderly shows that 60 percent of the individuals in the State who are elderly had incomes between $1 and $2,999; so roughly, 60 percent of the people 60 and above had incomes under $3,000; 17 percent were between $3,000 and $5,000; 16 percent were between $5,000 and $10,000; 4 percent were between $10,000 and $15,000; and 3 percent were over $15,000.

So you can see that by far and away the majority of these people are not affluent, contrary to popular belief in some quarters.

Professionals frequently find their clients put on waiting lists or unable to obtain personal home health services due to the disparity between the actual service cost and the reimbursement rate. As of September 1977, medicaid paid $7.50 for a home health aide visit while the average fee charged by private home health care agencies was $11. Adjusting the medicaid reimbursement rate for personal home health services would make these services more accessible to SSI recipients and other clients.

According to statistics from the Social Security Administration, 12 percent of the elderly in Florida are not covered by medicare and 2 percent of those that are covered have minimum coverage. Although most medicare eligible elderly have maximum coverage, including preventive medical benefits with a doctor's prescription, there are no bene-

fits in medicare for maintenance medical care or for custodial care, such as homemaker service.

Maintenance services are services provided to individuals who need help in daily living, or to prevent further deterioration of individuals with chronic physical and mental health conditions. The general purpose of maintenance services is to enable an individual to participate in the community to the fullest degree to which that individual is capable. According to statistics compiled by the Florida Program Office on Aging and Adult Services, nearly all the demand made on home health care agencies for therapy and social services comes from the elderly, while they constitute only 30 percent of the demand for skilled medical care. Without the maintenance and custodial care services, which are an integral part of community care for the elderly, many elderly persons would prematurely require placement in an institution where these types of services are provided through medicare and medicaid.

"SELF-FULFILLING PROPHECY"

Going back to the issue that you mentioned earlier, about the conflicting resolutions, we find that these services can be provided once these individuals are placed in an institution, while they cannot be provided while they are not in the institution, so it is a self-fulfilling prophecy in that respect.

Senator CHILES. Right.

Mr. LIPSCOMB. In 1977, the average State payment for medicaid patients receiving the lowest level of nursing care was $4,284 per year. In comparison, during the same year, the maximum annual cost for adult day care services was $2,860 per person. Besides the cost avoidance of developing alternatives to institutions for elderly persons, extending an older person's stay in his community far outweighs the potential negative effects of life in an institution and the lack of stimulation and personal care that often accompanies it.

Alternative living arrangements are programs high on the list of priorities in Florida. Our adult congregate facilities licensure program is at present assuring that over 600 facilities meeet established standards of personal care for over 18,000 residents with minimum care cost at approximately $2,400 per year.

Based on a 1972 HEW study of home delivered programs, approximately 34.2 percent of elderly program participants would require some level of institutional care if services were terminated. Through DHRS delivered and purchased services, an estimated 17,000 persons are receiving home delivered services at a maximum annual cost of about $2,000 per client. If 5,814, or 34.2 percent of these individuals, were in intermediate level II nursing beds, the total annual medicaid cost, as of August 1977, would be $24,907,176, in comparison to a maximum total of $11,628,000 for home-delivered services. This appears to lend credence to your statement earlier that it would appear to cost much less than to provide these services in the community.

As stated in the overview, the community care concept provides for a continuum of services, all of which may be needed in different combinations by any one person as he or she grows older. An isolated service geared toward the health or social needs of senior citizens is

not community care because that service focuses on a specific immediate need and may not provide whatever additional support services may be needed if changes in physical or emotional condition or consumers require a different type of service. Community care must include at minimum homemaker/chore services, personal home health maintenance care, home-delivered meals, and transportation. As resources allow, the minimum components of all community care programs in Florida must be expanded to include adult day centers, family home placement, leisure programs, and congregate meals.

It is our recommendation that services of a preventive or intervention nature, as previously described in our community care for the elderly services, be accessible to the elderly and that their access be simplified and consolidated with cash assistance programs by establishing universal, or at least equitable, eligibility and benefit standards.

In conclusion, I would urge the committee to consider a continuum of services for the elderly as represented by the department of health and rehabilitative services community care concept. In order to achieve this objective, existing or proposed Federal programs—such as the Older Americans Act, title XIX and title XX of the Social Security Act, welfare reform, national health insurance—all should provide coordinating rather than conflicting assistance to our increasing elderly population.

Thank you.

Senator CHILES. Thank you.

Billy Joe, we would be glad to hear from you now. We recognize the leadership role that you have been performing in the Florida Legislature in this regard, and especially in trying to keep some of these folks at home and with their families.

STATEMENT OF HON. WILLIAM J. RISH, CHAIRMAN, COMMITTEE ON THE JUDICIARY; MEMBER, COMMITTEE ON APPROPRIATIONS, FLORIDA HOUSE OF REPRESENTATIVES

Mr. RISH. Thank you very much, Senator. I would like to say I have a feeling, like President Kennedy once had, when the great brain trust got together for an evening meal. He said, "I think this is the greatest congregation that has been assembled since Thomas Jefferson dined here alone." I want to tell you that this is the greatest bunch of brains, and the greatest bunch of people I have been with in a long time, and I am glad for the privilege of being here.

I want to tell you, Senator, how grateful we are that you continue to stay in touch with the constituents back home, and how much we appreciate you coming back and being a part of leading this panel discussion in trying to find some ways to alleviate the problems of our senior citizens.

I want you to know that we feel about you in northwest Florida just like the Mexican, Jose, said they felt about him after he visited the United States. He had always wanted to go to the United States, and when he finally made it, he wanted to see a ballgame. Jose went to the stadium, but all the seats were taken. The only place they could place him was on top of the flagpole. When he went home and ex-

plained to his friends how much he had enjoyed it, they said: "How about the American people?"

He said, "They are wonderful, they are compassionate, they are understanding, they are real interested in you. You see, I could not find a seat, and I got up on the flagpole, and before the ballgame even started, they stood up and looked at me and said, 'Jose, can you see?'" [Laughter.]

You are just that welcome here this morning, Senator Chiles, and we feel just that much a feeling of love for you and your concern.

I want to say, first of all, that the bills we passed during the last session were not aimed at abolishing nursing homes, they were not aimed at abolishing the programs that are so wonderful, like the one that is part of the apartment where we are meeting this morning, but rather they are a viable alternative for those people who need an alternative situation.

There are a number of reasons why I think some home care for the elderly, through a subsidy program, is a better alternative than the nursing home. First of all, let me say that in many areas of this State, the nursing homes are overcrowded, and some of them, either through their own design or through trying to help too many people, are trying to take care of more of our senior citizens than they can adequately care for.

We passed some measures that would try to assure minimum care for the citizens in these institutions, but it still leaves much to be desired, and I don't think the people who run these institutions would disagree with that.

"Take Pressure Off Nursing Homes"

First of all, then, home care for the elderly would take some pressure off of the nursing homes in some of the areas of the State where they are overcrowded.

Second, let me say that people who have been studying our senior citizens and the problems they encounter, say there are two areas of outstanding trauma in the life of any senior citizen. One is when that person retires. This always brings about a great change in the life of a person when he or she gives up employment after 20, 30, 40 years and all of a sudden you get up at 6 or 7 o'clock in the morning and rather than going to the factory or school or somewhere else, you have a lot of time on your hands.

The second traumatic experience, we are told, is when for some reason or another, many times through ill health or through death or some other reason, the family unit is broken up. So it was these problems that we were aiming at.

Third, there is a great mass of people—if you listened to Mr. Lipscomb as he told us about the percentages and the incomes that our senior citizens have—there is a great gap in this country today, or in this State today, or there was prior to the last session for those people to get any assistance at home, they had to have more than $177 a month, but under $485 a month. Now, either of these groups qualified to go to the institutions and the Federal and State government would pick up from $535 to some $710, or $720, or $730, or something, if you wanted to put them in a nursing home.

Let me say that I lived with this problem for 10 years with my mother and father. My mother was able to care for my father in their home, and they were able to provide their resources. We lost my father this year. They didn't have to have help because they had a little bit of resources and it held out as long as mother and dad had to have it, but they fell in the gap between the $177 and $485 of income. So, any time we could have placed them in a nursing home, but we didn't. Mother didn't want him to go, and many members of the family agreed because as long as we could maintain that family unit, we wanted to maintain it, and we did.

I got to looking around at the vast number of people who fall in that income category, and I found out that even though we had passed a home care for the elderly bill in 1975, we had not done anything for people in that bill unless they had less than $177, and it is helping them a great deal.

A lot of the backbone of our Nation is comprised of these people in this group, who retire on these income levels. Now, if you have $2,000 a month income, or $1,000, or $1,500 a month income, you could pretty well take care of yourself and write your own ticket and go where you want to—not as much as you once could, but that is because of inflation. But, any more, these people that we were shooting at, were the instances in which they would not qualify for our community care program of 1975, but didn't want to go to the nursing home, and still could stay at home.

No Money for Home Care

Now, what did we provide for them? Well, first of all, I was very shocked when I found, Senator, that in the closing days of the legislature, I thought our program would have some $4.5 or $5 million in it. But because of the way the Federal regulations were written, and because of the way titles XIX and XX are written—I believe those are the applicable Federal sections—the Federal Government would be glad to help us send this group off to the nursing homes and pay from 75 to 90 percent, but they would not give us a dime to help keep them at home. So I wound up with $5,000 to be spent on a pilot program in a metropolitan area and a rural area. The Department has been very kind. They have decided that representatives of district 9 who received the rural section, which will be in district 2 here in Tallahassee—which I happen to live in, and I am glad they decided that was a good district—and they are going to pick a metropolitan area and use part in one and part in another, so we will know more about it next time. I am requesting—because basically of the same reason involved of the good things that I think can come to many people by allowing them to stay at home a little longer—that you assist us, perhaps, in getting the regulations changed and the laws rewritten, to where we could put up our State match and could help the people in this group.

Now, let me just comment briefly on what we are going to help them with. We are not going to say we have to have a medical doctor come into there, but if he has to, fine, we will do that. We are not going to say that you have to have a registered nurse come in there, but if one is needed, we will pay for it. We are not going to say that you have

to have a maid 2 hours or 4 hours a day, but if that is what is decided is needed, that is what we are going to do. If we need one meal cooked at 12 o'clock, we will do that. If we need a wheelchair, we will buy that. If we need a hospital bed, we are going to buy that. Whatever is needed to make a richer life for that person, we are going to try to do it, if this is the only alternative.

Now, there are a few people that might say, well, this is sort of mercenary because you are going to give a son some money or a daughter some money for doing what they ought to do anyway. If their income is under $435 a month, they are not going to have any money to waste, and it may well be that our schedule of payments which run from 10 percent to 45 percent of the amount expended for nursing homes and actual dollars—we are talking about a total supplement of $50 to $250 a month. We feel that that little bit of money in many instances, will go a long way toward helping a wife, or a son, or a husband, or a daughter, or some other loved one keep that unit intact. This may be the panacea, but it reminds me a little of the baseball game where they were playing the local team and the visiting team came in with all of its people. And for the local people, only the pitcher and catcher and one fielder showed up. But they went ahead and played anyway and they lost 28 to 0. The next night they had a community meeting to determine what they would do with their baseball team. This one old gent got up and said, "Well, the first thing we have to do is change pitchers." [Laughter.]

We have to do a lot more than change pitchers. We feel strongly enough and dedicated enough about this challenge or this ball game, if you would, that we are going to continue to enlist players and enlist your help and your support and we just are going to do a darn good job for our senior citizens for what they have done for us.

[Representative Rish submitted for the record the following report on home care legislation in the Florida Legislature:]

HOME CARE FOR THE ELDERLY: AN ALTERNATIVE TO INSTITUTIONALIZATION OF THE AGED

SUBSTANCE OF THE LEGISLATION

(1) The 1977 Florida Legislature passed a bill meant to supplement chapter 400 of the Florida statutes, relating to the licensure and regulation of nursing homes and adult congregate living facilities.

(2) The bill is an attempt to encourage the care of elderly citizens in family-type living arrangements in private homes, rather than in nursing homes or other institutions.

(3) Basically, the new law provides that the department of health and rehabilitative services shall pay to private individuals caring for the elderly a State supplement, rather than paying nursing homes to care for them.

(4) HRS has been directed to develop a schedule of payments by January 1, 1978. The payments are to be no less than 10 percent, and no greater than 45 percent, of the current rate paid to nursing homes for the lowest level of care.

Right now, the rate paid to nursing homes for the lowest level of care is $535 a month. Therefore, the payments under this new home care program will range from $53.50 up to $240.75 during the first year.

The rate of payment will be based upon the financial status of the person receiving the care.

Payments may be made for such things as: (a) Housing, food, clothing, and incidentals; (b) medical, pharmaceutical, and dental services not covered by medicare, medicaid, or insurance; and (c) specialized care required by the elderly person.

(5) To insure that the elderly citizens will receive good care, HRS has been directed also to establish minimum standards and procedures to be used in caring for the elderly at home. Under this plan, HRS will have standards by which to approve persons who wish to provide for an elderly person in their home.

(6) To be eligible for this program, the person receiving the care must be at least 65 years old and have lived in Florida for at least 1 year.

The person must also meet certain financial criteria, under either title XVI, supplemental security income (SSI) or the financial criteria established under the current statute for nursing home care.

Right now, the maximum income allowable for eligibility for SSI is $177.80. (There are about $20 worth of exclusions, so that the true maximum income level is about $197.80.)

The current maximum income level for eligibility under the nursing home program is $485 a month.

These figures create an inequity as far as care for the elderly is concerned. The poor are provided for under SSI. The rich, who make over $485 a month, may afford to be taken care of outside a nursing home. But what about the family who has an elderly member who makes too much to qualify for SSI, but is definitely not rich? If the elderly member makes less than $485 a month, he may qualify for State-supplemented care in a nursing home. Outside the nursing home, the family receives nothing. Therefore, since the family can't afford to care for the elderly person at home, the system forces them to place the person in a nursing home.

This plan alleviates that problem by making payments to qualified families who care for their elderly outside the nursing home.

INTENT OF THE LEGISLATION

It is generally agreed among people who study this sort of thing, that the rate of mental deterioration among the aged can increase substantially as a result of two things: First, upon retirement or loss of job; second, upon entering a nursing home or some other institution. There isn't a great deal we can do about the first one. We may push the dates back a little to allow a person to work longer; but most of us must stop working at some point, and many of us actually look forward to it and plan constructive alternatives.

But, as to the second problem, I think there is a lot we, as legislators, can do. At the very least, we can stop encouraging the institutionalization of our elderly citizens. We should see it not as a logical step, but as a drastic step, to be taken only when there is no other viable alternative.

With this bill, the Florida Legislature has provided a viable alternative. We are trying to encourage care for the elderly in the home. There are several reasons behind this. First, is the very practical reason that the mental health of our elderly citizens is just plain better when they can avoid institutions and remain in the "real world." At home, they can more easily keep up with what is happening in the world. They receive the stimulus of current events, seeing more of their friends and family and of being more independent than they would be in a nursing home.

The second reason is that most elderly citizens are happier at home. I don't think anyone actually likes being in a nursing home. To the young working stiff, a place where everything is done for you and where you do virtually nothing for yourself, may sound fine. But if you were to put that working stiff in the nursing home, see how long he wants to stay. Not long. Elderly people are no different. Age does not make a person some sort of alien. Age does not mean a person no longer wants to see friends and family or keep track of the world and participate in his society. Of course, age can take its toll; even chipper young men like myself wisely don't try to jump tennis nets. But I'm not ready to be locked away either. And if given a choice, I don't think I'll ever be ready for that.

The third reason for this alternative is that the legislature thinks it will be cheaper. Right now, the State pays, at the lowest level, $535 a month to a nursing home for caring for an elderly person and at the highest level, $680 a month. If that person were to stay at a private home, the State would pay a maximum of $240.75 a month. It costs more to keep someone in a nursing home because the home must have a fairly large staff to do many of the kinds of things that one's friends and relatives can do. Then, too, it must pay for a large amount of paperwork. In addition, there is the cost of such things as the building itself and the cost of maintaining it.

The legislature appropriated about $1.2 million in a lump sum for both community care for the elderly and home placement, with the understanding that about $500,000 would be spent on this new home placement program. HRS has been directed to submit a cost-benefit analysis next year that will tell whether the home placement method is, indeed, cheaper. I think it will be.

THE WISDOM OF FINANCIAL INCENTIVES

By and large, the people who make this country work are not the rich or poor—they are the middle income earners. They pay the most dollars in taxes, do the most work. Unlike the poor, they live fairly comfortable lives; but unlike the rich, they are not debt-free. They must work for what they have, and today more than ever, they must make vitually every penny count.

As far as I am concerned, it is the middle income earner that this bill was passed for. If a rich man has an elderly loved one, he can afford to keep that loved one home, where the family can care for him. The government has great programs aimed at helping the poor. But what about the wage earner who is not rich, or who doesn't qualify for Federal programs? He doesn't have the financial resources to keep his elderly loved one at home. But if he puts that loved one in a nursing home, the government will pick up the tab to the tune of $535 a month. Faced with this choice, what would anyone do?

Under this new plan, a middle income family that doesn't quite have the resources to care for its elderly members on its own will get a little help from the State and thus be able to give their loved ones the care and attention they require.

This, I think, should be the primary concern of the State in these matters. We should be attempting to hold the family unit together, rather than breaking it up. Yet, under the current nursing home care plan, the State is, in effect, offering incentives for the break-up of the family unit. Once the elderly are placed in the institutions, they are deprived of the warmth and closeness of loved ones. They miss out on things like watching their grandchildren grow. By the same token, the younger members of the family are deprived of the benefits of associating with someone who has been around awhile and seen a lot of life.

Under the home care plan, the State is offering an incentive to keep the family unit intact. The benefits are mutual between the family and the elderly. I believe a strong family unit has been an important factor in the development of our society. It's about time we once more recognize that the elderly can and ought to be an integral part of that family unit.

Thus, this plan is better for all concerned. The family is helped out, the State gets a break fiscally. Most of all, it is better for the elderly involved.

Senator CHILES. Billy Joe, if you would, I think it would be helpful to us if you could submit some kind of analysis [1] of what you run into in title XIX and title XX or other provisions of the law or regulations that handicapped your program from getting Federal funding.

We will now hear from J. Pomeroy Carter, who is here. If he will come up, we will put him on the panel. Dr. Bell, why don't you just come up and join the panel?

Mr. Carter, you may proceed.

STATEMENT OF J. POMEROY CARTER, EXECUTIVE DIRECTOR, ADVENT CHRISTIAN HOME, DOWLING PARK, LIVE OAK, FLA.

Mr. CARTER. Thank you, Senator Chiles. I apologize for being late. Some things came up this morning I didn't have any control over.

I appreciate the opportunity to speak this morning and I appreciate the invitation to appear before you in this hearing.

[1] See app. 1, item 1, p. 765.

During the past 16 years that I have served as administrator of the Advent Christian Home, located about 80 miles east of here, I have seen many changes that have taken place and observed many efforts to cope with and improve the care of the elderly here in Florida, and I believe that a lot of progress has been made. However, the impact has been diminished by the spiraling numbers of people who are reaching the retirement age. Just to illustrate this, in the year 1900, life expectancy for men was 47 years, and today it is 68; and for women today it is 75. I am not sure what that difference of 68 and 75 says to us, but that is the case today.

In Florida, we have 1.5 million people that are over 65 years of age, 17 percent of our population. By the year 2000, we understand it will be 25 percent of the population. I did a little calculating, looking at the fact that we have 300 licensed nursing homes in the State today with 31,000 beds.

If you take 5 percent of the people who will be over 65 years of age by the year 2000, which will be somewhere in the neighborhood of 3 million people, and if you take 5 percent of that, which represents the number of people that are in nursing homes on any one day, that means that we are going to need not 31,000 beds but 150,000 beds in this State by the year 2000. To me, this points out the urgency for us to find solutions or for us to find alternatives to cope with the needs of our elderly population. I believe that working together we can find affordable and workable solutions.

I am especially interested in what is going to happen in the year 2000, because that is the year I become 65, and I certainly hope we have some solutions which are affordable, not only for me, but for the taxpayers and for the whole social security system, and so forth.

Our place, the Advent Christian Home, is a little unique. We have what is called a total care concept—the full gamut of services. In the nursing home end of it, I have observed the efforts that have been made to improve the system. I have seen the constant parade of inspectors walking through. I have seen the mountains of paperwork that gobble up 3 to 4 hours of our registered nurses' time.

Senator CHILES. I think, for the record and for the people here, I should have identified you as the director of the Advent Christian Home, a nursing home in Dowling Park.

Mr. CARTER. Right, plus a total retirement community there with different levels of care, and this is why I want to lay this foundation, to show there are some community care programs which can work in relation with existing congregate living type of programs, to meet the needs of the older persons today, Senator.

I have seen the efforts to document or require documentation to assure that quality care will be provided, and yet none of us are so naive to think that documentation cannot be adjusted to meet the needs for inspection purposes. There does not seem to be much awareness or relationships between those who establish standards and regulations, and those who fund them, because I am convinced that today we cannot carry out the kinds of programs we all say we want in nursing homes, and the regulations and standards are trying to guarantee that we get for the amount of money that is available through the medicaid programs.

Medicaid Payment Gaps

Our home belongs to an organization here in the State of Florida, the Florida Association of Homes for the Aging, which is a group of nonprofit homes—this home where we are meeting today is a member of this organization. The average cost of care in our nursing homes, which have to be supplemented by donations and gifts because we are nonprofit, was $834 a month last year. Now, that is the average cost of care for all of our homes in the State, and yet, the most we can get from medicaid for the skilled nursing patient is $680, and that has only been during the last few months. It was $630 prior to that.

So I am convinced that part of the problems why we have the conditions we have, in many of our nursing homes, goes back to finances. I believe that reimbursement has to be realistic, and hopefully on January 1, when section 249 is implemented in the State, as I understand it will be, it will correct some of this problem.

I think another aspect of the problem is that there has to be more of an emphasis placed on prevention. Prevention and health maintenance has been completely cut out of the medicaid and medicare programs. I believe that an ounce of prevention is still worth a pound of cure, and if we are going to attack the problem in the years down the road, the year 2000 when we will possibly need 150,000 beds in Florida instead of 31,000, we must begin preventing some of the problems which cause people to be admitted to nursing homes.

Third, I think we should make an effort to attract bright, young people to go into health professions and specialize in caring for the elderly. We are still in the pioneering phase. Seventy-five years ago, life expectancy was only 47 years of age. We are just now having to cope with the problem of aging, and we are still groping to find the best solutions. We need more qualified people in this field, and we need funding for educational programs which will attract and which will prepare young professionals to cope with the problems of older persons.

I also believe we need more nonprofit long-term care facilities. I am not against the proprietary nursing homes. I am not against private enterprise, but I do believe the records will show that the higher quality of care being offered the elderly today is through the nonprofit segments.

Most nonprofit programs have been housing programs. You—the Federal Government—have sponsored these programs in housing. You have built beautiful facilities such as this one—the Georgia Belle Dickinson Apartments—or made it possible for nonprofit groups to build facilities like this. I think it is time we began emphasizing the comprehensive approach to caring for the elderly. In addition to housing, nonprofit groups should be strongly encouraged to get involved in providing nursing care and a full range of supportive services in the community and using their facilities as the base from which they operate.

The most effective alternatives to institutionalization are supportive services in the community, making it possible for older persons to remain in their own homes and feel secure just as long as possible. I would like to see us develop more of these comprehensive programs in such established institutions as we have here.

Let me share with you a little about why I am involved in the type of program I am, and why I recommend this type comprehensive program.

In 1960, I attended Florida State University and received a master's degree in social work. While there, I was placed at the Jewish Home for the Aged in Miami for a 6-month internship. A part of my responsibility was doing intake studies, going out and working with people who wanted to enter the Jewish home.

I became very impressed and quickly realized that what these people were looking for was primarily security; they had lost their spouse, their children were many miles away, possibly in other States. They were beginning to wonder: "What is going to happen to me when I cannot drive my own car, when I cannot do my own shopping, when I cannot get back and forth from seeing the doctor? What would happen if I fell and broke a hip?"

Comprehensive Program

So they had begun to look for a place where they could go ahead and begin living on an independent level and basis, but yet have the security of knowing that if I should get to where I cannot provide for myself, there will be someone there to do it for me.

So when I returned to the Advent Christian Home to work with our board in developing a program there, I was convinced that it should be a comprehensive program. Today, we offer four different types of living arrangements so people can live as independently as possible. We offer an intermediate care facility, levels 1 and 2, and a skilled nursing facility. We have an outpatient clinic where our staff practices preventive medicine and health maintenance.

A unique thing for us is that on the same campus we have a children's home, and I don't recommend this for everyone, but I think it emphasizes that people need to feel that they are still a part of the community, that they are not isolated, that they are still in contact with what is going on and aware of what young people are thinking.

When the Florida Legislature passed a law establishing some demonstration projects around the State to find alternatives, they developed the community care for the elderly program, and we were asked to demonstrate community care in a rural setting. We just got this program funded and underway the first of this month. It is fairly easy, we have found, to move into this type of program by using our present facilities as the hub and working from it. We are reaching out in a mile-and-a-half radius of the home. It was fairly easy to just broaden the services we have already been offering, such as telephone reassurance, the day-care program and activity center, and bringing people into it. We had our congregate meal program, we just broadened it and developed a delivered meal program from it.

We have initiated homemaker and housekeeping services, home repairs, and home health service; nurses, doctors, and therapists can now go into the homes if it is needed and necessary. We are also providing transportation.

These are the supportive services that I feel are needed in every community if the people are to feel secure and be able to remain in their own homes.

We all know that there are people in nursing homes that should not be there, but the reason they are there is because many of them are fearful or they cannot get the care they need outside a nursing home. So the goal of keeping a person active, alert, and functioning independently in a secure environment should be, I think, the goal of all of our community care programs.

Personal Care Level

I see the real gap in our present program at the Advent Christian Home as being at the personal care level. This is the level between apartment living and intermediate care level one. These are people who cannot live in their own apartments; they are beginning to become forgetful. They need to be reminded to take their baths, to change their clothing, to take their self-administered medications. They need some help in cleaning their rooms and so forth. This is a personal care level—not nursing care.

We have not developed this level of the program, however, for one reason—we cannot afford to do it for what the maximum payment of SSI is—and that is $200 a month. We cannot provide three meals a day, personal service, and housing for that amount. So actually, when a person gets to the point he cannot live in his apartment, we have to move him into the intermediate care facility, where we can get $530 a month from medicaid. That emphasizes a point that there is a gap there, where for $350, we feel we could offer the personal services and have a savings of $185 a month, if funds for this level were available.

So this morning, I would like to urge that in considering community care programs that you, Senator, and your committee promote and finance the development and operation of comprehensive senior centers, preferably tied to and affiliated with housing projects such as this one. Your section 236 and your section 202 projects already have a nucleus of some of these services.

Also, I would like for you to consider expanding the title XX program, or to create a new program, whereby these centers can operate 7 days a week instead of 5 days a week.

Meals Only 5 Days

Senator Chiles. I think that is a very good point. I find that this place can only serve meals 5 days a week, and has a full kitchen that is not being utilized, and that there are no meals being served on Saturdays and Sundays, and it just does not make sense. We have too big of an outlay and too big of an investment here to only be utilizing it to that extent.

Mr. Carter. Absolutely. Of course, it is assumed the other meals are taken care of by sons and daughters or relatives who are home with the older person on weekends. So the one meal a day, Monday through Friday, and not on Saturday and Sunday, was geared for the older person who lives with someone else who is possibly working, but there are a lot of people in this State who live alone and have no one to care for them.

Certainly, I think we ought to expand the program to include two to three meals per day instead of one, for those who cannot provide

for themselves. If we are to keep persons out of nursing homes, they will need three meals a day. If senior centers are tied to a facility like an adult congregate living program which has a central dining room, it will not be that much greater a problem to be able to expand the program to become a multiservice senior center, if funding is made available.

Another thing is that we have had trouble with title XX, and we delayed starting our program until general revenue funds were made available from the State, because I said there is no need to start—there is no way to find viable alternatives to institutionalization with one meal a day 5 days a week. We had to have funds to do it 7 days a week, and have emergency services 24 hours a day.

The title XX program is restrictive in other areas, also. It does not provide for any startup funds. It is only for the indigent, and there has to be matching funds. Now, I think that if you are really going to get nonprofit organizations to sponsor this type of program, the regulations have to be broadened, and the program has to be made more attractive.

The last point I would like to emphasize is that we find ways to encourage young people to go into the health professions and study to care for older persons. When I went into the field of caring for the aging, especially the nursing home end, I was told that I was committing professional suicide. If you ask many people in the nursing profession and in the medical profession today, they will let you know in one way or the other that nursing home care is still the low man on the totem pole for health care professionals. Caring for the aged, it is assumed, is for the incompetent person, the person who cannot get a job anywhere else, or it is for the person who is dedicated to really do something where there is a lot of need for such services.

We have been privileged to have good physician coverage, and we kind of stumbled into it. First, I could not get the kind of physician service at Dowling Park that was required to be certified for medicare.

One day, becoming very frustrated with inadequate care, I went across the river to a little clinic in Mayo, Fla., that was being operated by the University of Florida College of Medicine, as a project of their community health and family medicine program. I talked with Dr. Richard Henry and told him my problems. He agreed to come over and look over our facility, but made no commitments to help.

After he came over and had spent several hours with me, he said:

> I want to just share something with you. We have been looking for the last 2 years, within a 100-mile radius of Gainesville, to find a nursing home that we could conscientiously place our students in so they could get some experience in geriatric care, and we had not found one until today, when I came to your place.

I don't say this to brag, but he was looking, we realize that. He said: "I think we can work together here and meet both of our needs."

Medical Students in Nursing Home

So a program was worked out 7 years ago to rotate medical students and physician assistants, students through our facilities, that they might begin to get some exposure, training, and experience in geriatric medicine. This program has become far more than I ever dreamed it

would be. I have seen young people get real excited about working with the elderly. I have also seen them come with a very skeptical and very resentful attitude, only to leave feeling real good about their experience working with the older person.

I believe we need to look at this problem just like we did at general practitioners, family practice physicians, and the need for services in rural areas a few years ago. I believe it was, at that time, the legislature here in the State said that for every dollar we fund the college of medicine, a certain percent of it has to go to the training of the family practitioner and community health person. It worked, and I believe that such teeth should be put into the college of medicine funding programs today, to get persons to go in the health care profession and train to better meet the needs of this older mushrooming segment of our society that is going to be a much greater problem by the year 2000, if we don't find some workable and affordable solutions today.

Thank you, Senator Chiles.

Senator CHILES. Thank you, sir.

Is Dr. Reynolds from the community?

Mr. CARTER. Yes; he is head of the department of community health and family medicine at the University of Florida, which works with us.

Senator CHILES. We had him as a witness yesterday in Gainesville, and he said he thought the health care now in your institution was about the best he had seen in the 25 years he has practiced medicine, so that program seems to have worked out beneficially for both you and the university.

Mr. CARTER. Yes.

Senator CHILES. Dr. Bell, we are delighted to have you with us today. We would like to hear from you, from your vantage point as the director of the multidisciplinary center on gerontology, institute for social research, Florida State University.

STATEMENT OF WILLIAM G. BELL, PH. D., DIRECTOR, MULTIDISCIPLINARY CENTER ON GERONTOLOGY, INSTITUE FOR SOCIAL RESEARCH, FLORIDA STATE UNIVERSITY, TALLAHASSEE, FLA.

Dr. BELL. Thank you, Senator Chiles.

I am delighted, of course, to express the same point of view of others at this hearing, that you are here. I always like to see you in your walking boots. I am happy that you have come to Florida to raise the issue of alternative care for older people.

I wonder if I should not start my brief remarks by indicating that I was not supposed to be in Tallahassee for these hearings; however, my travel plans changed, and I am happy to be here. I will have for you later a much more well-thought-through, elaborate statement.

Senator CHILES. Your statement will be made a part of our record.

Dr. BELL. Thank you very much.

[The statement follows:]

STATEMENT OF DR. WILLIAM G. BELL

ALTERNATIVES IN LONG-TERM CARE FOR THE ELDERLY: A FLORIDA PERSPECTIVE

Senator Chiles, I join with others at this hearing to welcome you back to your home State. Let me add my words of commendation to you, to the special com-

mittee, and to committee staff for holding a new set of hearings on issues affecting community health services and long-term care for older Americans. It is an area that cannot be permitted to lie fallow; we in the field are grateful to the committee for its sustained interest and activity in this matter.

For purposes of identification, let it be indicated that my gerontological activities are not confined to academia but include additional responsibilities. I serve as director, Multidisciplinary Center on Gerontology at Florida State University, currently operating in the second year of a developmental grant from the U.S. Administration on Aging. Additionally, I serve as head of the committee on aging, Florida chapter, National Association of Social Workers. In a consulting capacity I am active, on occasion, with the Federal Council on the Aging, primarily with respect to helping develop a national policy on the frail elderly.

A priority of my gerontological activities, both in research and social action, particularly since my arrival in Florida approximately a decade ago, is the matter of long-term care for older people, especially for elderly with low income. For example, in 1970–71, I was commissioned to undertake a policy study of one aspect of long-term care for Florida's medicaid elderly for the Department of Health and Rehabilitative Services (HRS). The report was published in 1971 under the title of "Community Care for the Elderly: An Alternative to Institutionalization." The report provided early information that medicaid, or title 19 of the Social Security Act, while designed to deal with the long-term care needs of poor elderly, fell far short of that goal in this State by reason of its bias toward institutionalization. There were other conclusions reached by the study which will be part of my testimony as we proceed.

My formal statement is offered in two parts. After an introduction, there will be a brief recapitulation of Florida's efforts to develop community based care comparable to institutional care for impaired elderly, an effort dating back to 1971 when the aforementioned study was published and its recommendations later enacted into State legislation. The second portion will offer a series of recommendations for committee consideration stemming in part from our experience and struggle to develop alternatives in long-term care for older Floridians.

PROGRESSS TOWARD COMMUNITY CARE FOR THE AGING OF FLORIDA

It is presumed that the health care for older Americans, which represents the focus of this hearing, refers essentially to long-term care, that is care precipitated by a chronic condition or ailment suffered by an elderly person creating a dependency on others to sustain the normal activities of daily living. As Albert Wessen suggests, long-term care is frequently an outcome of chronic illness, for it "often implies a situation in which medical management is relatively static, the opportunities for improvement or recovery are relatively limited, and the involvement of the physician hence is often not intense."

If one accepts this definition then it is important to understand that long-term care has both social as well as health facets, hence, the care required may be in some instances largely social rather than medical in nature. In many instances the problems addressed by long-term care services represent an overlay of multiple health and social difficulties, rarely a single problem.

When care is to be provided to impaired elderly who are deemed to be dependent on others for life support, perhaps for an extended number of years, then one issue is this: Where shall such care be provided, in the institution or in the community? In my view, this is the heart of the furor over alternatives, of the debate over national policy on long-term care, and of current and future demands on the public fisc. We can differ on many of these somewhat complex issues but on one thing we ought to be in agreement, namely, that long-term care is to be provided to impaired elderly residents either within the institution or in noninstitutional settings. The crisis in long-term care, and there is little doubt it is of crisis proportions, is that current policy is clearly biased toward the institutional solution, supported in large measure by use of public funds under medicaid. I am among the group of gerontologists critical of present policy and practices and the consequent inequities for elderly (and their families) who prefer to remain at home but are currently without effective long-term care services comparable in any meaningful way to care provided through the institution.

The inequity in long-term care practices is given further emphasis when it is recognized that some 4 to 5 percent of all elderly in the United States are currently resident in an institution, be it nursing home or State hospital and the

like, but approximately three times that number or about 12 to 14 percent of the elderly in this country reside at home and require long-term care in some form. The tenacity of the institutional slant to national policy is all the more puzzling in view of the personal preferences expressed by impaired elderly. When older people in need of long-term care are polled, whether resident in institutions or still at home, at least 85 percent of either group, express a strong preference for living out their remaining years at home. Many in institutions want out, most of those out want to remain out.

This is not to suggest that institutional care may not be a necessity and an appropriate solution for selected impaired older people. My criticism of institutional care centers on the observation that national policy has structured but one alternative for elderly in need of long-term care, certainly for low income aging receiving medicaid. Moreover, institutionally based care and community based care should be viewed not as competing systems but as elements of an interacting program of long-term care. As I have stated on another occasion, a rising demand for alternatives to institutional care is largely a strong plea for a change in allocation of present resources in support of a more equitable long-term care delivery system. Jerome Kaplan put it this way: "What is essential is a rational approach which recognizes parallel care systems; the necessity for intimate interaction of these systems; and the recognition that if all systems operated as part of an integrated large entity the push for alternatives would be recognized as a push for a complete range of choices through a continuum of services."

It is because of this reasoning that we should abstain from use of the phrase, alternatives to institutionalization, and begin to employ the more appropriate terminology of "alternatives in long-term care" as suggested by the committee's staff director and others.

Florida's progress toward developing alternatives in long-term care exhibits some limited progress dating from the publication of the HRS study corroborating the inappropriate and premature placement of a proportion of medicaid elderly in nursing homes in the county surveyed. According to the informed viewpoint of professional nurses in the homes studied at that time, at least 30 percent of all medicaid patients admitted the prior month could have remained at home if a program of community care had been available at the point of entry to the institution.

Two years after publication of the HRS study the Florida legislature enacted the Community Care for the Elderly Development Act of 1973, but without implementation funds. Therefore, HRS felt unable to pursue the legislative mandate to test a proposed demonstration of community care consisting of five basic home delivered services to be provided through a single public agency: (1) health maintenance, including bedside nursing; (2) home help such as housecleaning, laundering, meal preparation, marketing for food supplies, and the like; (3) mobile meals brought regularly into the home as needed; (4) transportation service to enhance mobility of elderly seeking accessibility to physician and other essential services; and (5) counseling, crisis intervention, and advocacy, furnished by professional social workers aided by indigenous staff to ensure consumers that the promised services were delivered, and to serve in emergencies for impaired elderly around the clock.

The act lay inert until 1976 when the Florida Legislature passed the Community Care for the Elderly Development Act of 1976, updating and extending the prior act passed in 1973. The 1976 act, now Florida statutes, chapter 409.3621-30, calls for the Florida HRS to undertake and supervise the testing of four optional models of programs likely to perform as effective alternatives in long-term care for impaired elderly. These four models are: (1) a package of home delivered services, somewhat along the lines of community care proposed by the 1971 study report; (2) a package of services for elderly offered through a multiservice senior center; (3) a program of family placement whereby a family member at home is reimbursed for caring for an elderly relative, including those returning from the institution; and (4) day care, more or less along the now well established pattern of medical and social care for elderly overnighting at home but spending their days at a medically oriented center within the community. The 1-year demonstrations have recently gotten underway and will be evaluated by HRS staff by July 1, 1978, to ascertain the degree to which these optional models of service act as an effective deterrant to institutionalization or a way of returning to the community the mentally disabled currently in State hospitals.

Seven projects have been selected for testing, offering four alternative forms of care in the community. The legislature voted an appropriation of $500,000 for one of the four alternatives, namely, family placement. By assembling funds from general revenues plus a small amount from titles III and VII of the Older Americans Act, approximately $1,240,000 has been assigned to fund the demonstrations which were initiated August 1, 1977. For the record, the seven demonstrations are:

Location	HRS district	Demonstration sponsor	Model tested
Pensacola	1	Escambia County Committee on Aging.	Home-delivered package.
Tallahassee	2	HRS Aging and Adult Services Program Office.	Family placement.
Dowling Park	3	Advent Christian Home	Multipurpose senior center.
St. Augustine	4	St. John's Citizens Advisory Council on Aging.	Home-delivered package.
Margate	10	Broward County Area Agency on Aging.	Multipurpose senior center.
Miami	11	Greater Miami Jewish Federation	Combination of multipurpose senior center and home-delivered package.
Do	11	Douglas Gardens (Miami Jewish Home and Hospital).	Day care in hospital setting.

Since the problems of long-term care for older people fall most heavily on those with low income, and since the national supplementary security income (SSI) income maintenance program and medicaid are most directly of import to elderly with limited resources, it may be helpful to this committee to review recent data associated with these two programs in this State. Table 1 provides information on medicaid supported elderly in Florida nursing homes matched with their numbers on SSI for the current year and the 3 years prior.

TABLE 1.—MEDICAID ELDERLY IN FLORIDA NURSING HOMES ON SSI (OAA) ROLLS, 1973–77

Year	Average monthly number on SSI (A)	Average monthly number of residents in nursing homes (B)	Col. B as percent of Col. A (C)
1973–74	[1] 72,080	10,660	14.7
1974–75	86,902	11,327	13.0
1975–76	[2] 92,428	12,649	13.7
1976–77	[2] 89,872	21,537	24.0

[1] Elderly refers to individuals 65 years and over. Note that SSI replaced OAA Jan. 1, 1974. Data for years 1973–74 through 1975–76 derived from HRS annual statistical reports; data for fiscal year 1976–77 derived from PLO 44 computer runs not published as of the date of this testimony.

[2] Another report places the total number of elderly drawing SSI, as of December 1975 at 95,860, in which case the ratio in col. C would be reduced to 13.2 percent.

[3] Average figures for fiscal year 1976–77 include skilled nursing care, intermediate nursing care, and general care nursing homes—the latter program initiated in May 1976. The years prior to fiscal year 1976 included only the 2 categories of skilled and intermediate nursing homes.

Source: HRS, statistical section. Personal communication Nov. 18, 1977.

It is known that approximately 7 percent of Florida's population 65 years and over currently draw SSI benefits. According to table 1, approximately one-fourth of this subset of the Florida population of elderly are resident in/nursing homes in the State with the aid of medicaid funds. At present, Florida offers long-term care via three categories of nursing homes: skilled, intermediate, and general. Does the finding that one-fourth of the low-income impaired elderly are occupying nursing home beds represent good or bad news? One may suppose it is good news in the sense that the two ratios reported are precisely the same as the equivalent ratios reported in the 1971 HRS study on medicaid-old age assistance clients in nursing homes in the State. It may be viewed as bad news when it is acknowledged that in the 6 years since 1971 Florida has made no serious inroads in reducing the rate of institutionalization of low-income elderly requiring long-term care. Obviously the lack of change may in large measure be

attributed to the lack of alternatives in long-term care available to Florida's elderly on the medicaid rolls.

Additional relevant data on the financial costs of nursing home care provided to medicaid elderly over the past 4 years adds further impetus to the need for reviewing current State practices on primary utilization of the institutions for functionally impaired elderly. The data is displayed in table 2.

TABLE 2.—SELECTED COST DATA ON FLORIDA MEDICAID ELDERLY BY CATEGORY OF NURSING HOMES, 1973–77

Fiscal year	Average monthly number of residents	Total resident-days	Total payments	Average payment per recipient	Average cost per day
			Skilled care nursing homes		
1973–74	9,755	3,506,715	$37,615,658	$321	$10.73
1974–75	10,271	4,372,248	54,978,491	446	12.57
1975–76	[1] 10,282	3,797,754	51,419,341	451	13.54
1976–77	7,477	2,754,884	41,905,158	467	15.21
			Intermediate care nursing homes		
1973–74	905	326,039	$2,470,305	222	7.38
1974–75	1,058	463,909	4,412,849	348	9.51
1975–76	[1] 1,971	712,327	7,710,332	354	10.82
1976–77	5,282	1,937,324	25,237,104	398	13.03
			General care nursing homes		
1975–76	396	12,354	$140,913	356	11.41
1976–77	8,778	273,036	3,099,181	353	11.35
1976–77 (total)	21,537	4,965,244	70,241,443	[2] 353–467	[3] 11.35–15.21

[1] Average figures for fiscal year 1975 do not include July 1975 due to a prior payment of July funds.
[2] Average, $410.
[3] Average, $13.19.

Source: HRS statistical section, December 1977. Personal communication.

A comparison of the financial costs, in Federal and State dollars, of the present pattern of institutionalization of medicaid elderly in need of long-term care in Florida reveals that costs have more than doubled in a 6-year period. In 1971, the year the HRS study report recommended changes in State approaches in long-term care, Florida spent $30 million plus on institutional care for medicaid elderly. By fiscal year 1976 the comparable total had risen to $70 million plus. Given the current inflationary trends in costs of most forms of health care, it is highly likely that the costs of institutional care for older people supported by public funds will grow inexorably unless there are new programs of diversion from the institution as a consequence of new National-State policies on long-term care.

In summary, the experience in Florida with its limited efforts to develop community based care alternatives for its chronically ill elderly confirms one of the statements in your opening remarks at this hearing. Namely, there is yet to emerge at the national level a systematic approach to this pervasive problem which bears promise of developing a cohesive program of long-term care for older Americans. The attempt in this State to mount a set of demonstrations as alternatives in long-term care were State initiated with little or no direct assistance from Federal legislation. It is not that we are unhappy with State initiative but rather that there are no national mechanisms to support such initiatives.

The major national program offering long-term care for the aging lies embedded in title XIX of the Social Security Act, or medicaid. But the inherent difficulty with medicaid as an affective program of long-term care is that it was not designed as a service delivery system for long-term care but to act as a funding mechanism to purchase some forms of long-term care, essentially institutional care, for some low-income elderly. This is not bad but it is just not good enough. In fact on analysis one can perceive that the major Federal emphasis in long-term care for older Americans is on providing a hodge-podge of funding approaches not on the development of a cohesive service delivery system of long-term care for the elderly. Consider, for example, the range of Federal funding approaches for long-term care, when at least eight major programs have some

jurisdiction and offer reimbursement on aspects of long-term care for diverse older people: Aid to families with dependent children (AFDC), social security benefits, supplementary security income (SSI), medicare, medicaid, Veterans' Administration benefits, and title XX Social Security Act.[1]

RECOMMENDATIONS FOR FEDERAL ACTION

Clearly, the policy issues swirling around long-term care for the elderly in the United States are exceedingly complex, involving at a minimum policies affecting program funding, equity for the chronically ill at home on a par with counterparts in nursing homes and other institutions, intergovernmental relations in current and future programs of long-term care, intergenerational relations and filial responsibilities of adult children with chronically ill aging parents, reform of institutional practices, and expansion of community based programs for elderly at home not requiring institutionally based services. Given these complexities, it would be foolhardy to suggest technical and administrative changes or policy redirection without a more exhaustive analysis of national data.

Nevertheless, it is equally clear that to admit the issues are complex is not to infer inaction but to suggest a renewed desire to engage with the pertinent issues, sort them out as systematically as possible with the information at hand, and begin to identify potential directions for change.

It seems to me that whether a national strategy emerges of moving comprehensively or in piecemeal fashion on the problem of long-term care for older Americans, some observations can be offered with respect to the general direction to be taken by national policy with respect to long-term care for older Americans.

(1) *Establish a national research/demonstration program to test soundly designed alternatives in long-term care for the elderly*

It seems axiomatic that changes in policy direction have to occur at the Federal level, hence some experience must be devised which encompasses a national perspective. Long-term care is a national issue affecting elderly in all States, and medicaid is a national program requiring changes in national policy before States can act appropriately.

The elderly population at risk are likely to be those in the upper ranges of the age spectrum particularly those around 75 years of age and over,[2] females, individuals with low income, and minorities. In light of these variables some breadth of demonstrable experience would be useful before initiating changes in national policy. It is likely that no single State can mount the financial resources to cope with demands engendered by stable programs of long-term care. Good fiscal sense suggests the need for experimentation and testing of alternative models of long-term care prior to launching a major national effort. Let there be established a national source of funds to enable willing States to develop the necessary data on costs and effectiveness of soundly conceived variations in long-term care for older people.

(2) *A cohesive policy of long-term care for the elderly should include both community based and institutionally based program elements*

Specifically, at least four programs ought to be included in a national policy on long-term care for the aging.[3] These are: (a) The prevention of inappropriate institutionalization through the provision of community based alternatives; (b) release to the community of all institutional patients who have been given adequate preparation for such a change; (c) establishment and maintenance of community support systems for elderly emerging from the institution, and (d) reform of institutional care and practices to reassert the health and human rights of institutionalized elderly for whom a program of institutional care on a temporary or long-term basis may be necessary.

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[1] Tom Joe and Judith Meltzer, "Policies and Strategies for Long-Term Care," Long-Term Care and Health Administration Quarterly, Vol. 1, No. 3, Fall (September) 1977. Joe and Meltzer indicate further that 32 percent of total medicaid State and local long-term facilities expenditures in fiscal year 1974 went to skilled and intermediate nursing homes.

[2] One effort in developing a rationale for a program for individuals aged 75 years and over may be found in "A National Policy on the Frail Elderly," published by the Federal Council on the Aging, Washington, D.C., September 1976.

[3] The initial three may be attributed to Dr. Bertram Brown, National Institute of Mental Health, in "Deinstitutionalization: An Analytic Review and Sociological Perspective." NIMH Series D, No. 4, U.S. DHEW, ADM 76-351, Washington, D.C. We have modified Dr. Brown's formulations slightly for general applicability.

(3) *Long-term care has both social as well as medical aspects, and responding to the former is highly important for elderly with long-term needs*

Why draw attention to the obvious? Because the dominance of medical practitioners in long-term care tend to ignore the flagrant disregard of social problems in favor of medical ones. Institutional placement may be generated by social inabilities such as maintaining a household in physical decency, ability to prepare one's meals, the absence of transportation for needed mobility to essential health or social services and the like, subject to an overlay of a health or medical problem which tends to blur the saliency of the social quality of the dependency engendering condition. Yet in the significant absence of attention to the social requirements of the afflicted individual one is precipitated into an institution whose function is largely medically oriented, and the subsequent relinquishment of normal decisionmaking on the part of the elderly individual. The paradox of our method of dealing with impaired elderly, to paraphrase the late Margaret Blenkner, is that once an impaired older person has been made the object of our concern, he or she may be reason of our distorted service provisions and perhaps our thinking, become the object of our coercion in the form of inappropriate institutionalization.

(4) *As a precondition for selection of an appropriate alternative in long-term care, a psycho-social-medical assessment of the impaired individual should be the basis of the alternative selected*

In a sense this recommendation tends toward the ideal. In defense of families and social workers involved in long-term care, a decision to institutionalize the impaired individual acknowledges the limited local community-based service programs to serve the older person desirous of retaining one's domiciliary residence. However, despite the realistic constraints of too few service options at the local level, any formulation of a long-term care plan should be infused by a more rational approach than is currently in vogue.

National policy of programs such as medicaid should require that the process of selecting the mode of long-term care rest on a psycho-social-medical assessment of the older person. This evaluation can be assigned either to a designated professional such as nurse or social worker, or to a team of professionals including a nurse and social worker. Physician records rather than a physician should be utilized to hold down costs of the assessment.

Out of this kind of procedure can one expect to design a service plan which takes into account the individual long-term care needs of the older person, and the differences in local services. Out of this systematic procedure can one expect at least the following benefits: (a) Selection of a treatment setting deemed most effective for the older person's health and social conditions, (b) gather hard data on the gaps in local service delivery systems for the elderly, and (c) utilize the long-term care facility more appropriately for impaired individuals whose long-term care needs can best be served by a designated institution.

(5) *Establish long-term care councils at National, State, and local levels of government to analyze, plan, and design improved long-term care programs for impaired elderly congruent with the concept of alternatives in long-term care*

Given the saliency of long-term care and its vital role in the health of older people in the United States, and the emerging need to plan more effectively in this area, establishment of long-term care councils (LTCC) at the three levels of government is recommended.[4]

At the national level, current policies and programs on long-term care would be reviewed by the LTCC and feasible legislation proposed and sought. At the State level, a cohesive approach as outlined in recommendation No. 2 above would be the focus of the State LTCC, involve the diverse State units related to each of the subelements to develop and implement a State plan on long-term care. On the local level, a LTCC would have at least three functions: (a) To establish improved screening procedures for medicaid referrals of elderly to local nursing homes, (b) to review the feasibility of expanding programs such as day programs to assist the elderly in remaining in their homes or place of local residence, and (c) to serve as coordinative mechanisms for the delivery of community based services, monitor institutional performance, and as a resource and advocate for families with elderly in need of long-term care.

[4] Undoubtedly there are many LTCC already in existence in the United States. One such experiment can be cited: the Long-Term Care Committee of the National Capital Medical Foundation, 1828 L Street, NW., Washington, D.C. 20036.

Dr. BELL. Let me make a few off-the-cuff remarks about the issues before us with respect to long-term care for older people. Clearly, for most people in the country, the major health issue is acute care, but for older people the concern is around long-term care, because older people are highly vulnerable and subject to chronic illness. As a result, long-term care is the critical health issue.

I think an additional point I want to raise at the start is the need to correct a phrase which I, along with other gerontologists, promoted, and that is "alternatives to institutionalization." As you pointed out in your remarks, there may not be an alternative to nursing home care for some older people. I think a better phrase now being used in the country—and I am indebted to your staff director, Bill Oriol, for this—is alternatives in long-term care.

In suggesting the importance of alternatives in long-term care, it seems to me then we have to admit that we do not really have in this country a system of long-term care. When we do, and perhaps in time we will, it would have to contain, in my view, at least a three-pronged approach.

First, it should include the provision of community-based care as a form of prevention to avoid institutionalization, which may be inappropriate or unnecessary.

Mr. Lipscomb suggested about 16 to 30 percent of elderly people now entering the institution may well be there because of the absence of other forms of long-term care. I think that estimate is well founded, though some gerontologists suggest it might be higher.

A second approach, it seems to me, is the matter of returning to the community people now in the institutions who ought not to be there—and we ought not to ignore the fact that they are there.

Senator CHILES. Or returning them timely.

Dr. BELL. Right. For example, by careful screening and selection, some elderly at Florida State Hospital in Chattahoochee, as well as other such hospitals, a substantial proportion of those institutionalized elderly can be helped to go back and live at home.

I think we should acknowledge our debt to State Representative Billy Joe Rish for the program of deinstitutionalization that he has generated in this State.

The third element, as part of a long-term care policy, it seems to me, is the issue of improving care within long-term care institutions so that those going in will in fact have the kind of care they deserve and need.

Perhaps what has not been addressed so far is: Who are the institutionalized? There have been some studies on this question. Institutionalized elderly tend to be essentially those who are older, sicker, poorer, and without family. It seems to me that we have not sufficiently acknowledged that the people who are in nursing homes appropriately, and I do not denigrate nursing homes, are clearly those for whom there is no optional alternative care at home. However, there are many older people being cared for by families, in far greater number than the 4 percent or so institutionalized, yet families receive little or no help whatever from Federal long-term care programs.

For example, while Mr. Lipscomb points out about 4 percent of the elderly of this country are in institutions, I believe at least double that number—8 percent, according to information from one study by

Shanas—are living in one-bed hospitals at home, being cared for by family members. As Representative Rish indicated, there is absolutely no way that these families can, at this time, receive help from Federal programs to support their efforts, in contrast to the effort spent on those who go to institutional facilities.

For the past 9 years I have been following the gradual but unmistakable rise in the number of low-income elderly entering nursing homes in this State, dating back to a 1970 study of Florida nursing homes. At that time the percentage of medicaid elderly living in nursing homes was around 40 percent or so. It is now up to 60 percent and still climbing. I believe the percentage is the same for the entire country. In other words, we are seeing a gradual populating of nursing homes with low-income elderly, for whom there appears to be no other long-term care alternative. I think the difficulties in obtaining long-term care by older people are very real and very telling, for while this State is prepared to spend, with Federal assistance, something like $600 a month for care in an institution, it is not able, by reason of Federal restrictions and policy in title XIX of the Social Security Act, to be able to pay anything equivalent for similar care at home.

Senator CHILES. I think that is a very valid point and I think that we have to be careful. Even in my opening remarks, I think the statement could have been interpreted that alternative forms of care will allow us to reduce the amount of money that we are expending now, because we are spending more in the nursing home. I don't think that is true. I think it would be wrong for us to try to say that, because I don't think it is going to be cheaper. I think we are going to see our costs go up, because even with the Rish bill, we are going to touch a lot of people who are living in a terrible situation now, and that is going to improve their conditions, but it is going to mean some more dollars.

FORCING PEOPLE TOWARD INSTITUTIONAL CARE

What you point out is valid. We are now forcing people toward institutional care, and as these other people are found or as they or their relatives find the program, it will mean that costs are going to escalate at the highest dollar. So we are not going to be offering the kind of human care that we could offer, and the dollars will continue to rise. I think what we are talking about now is going to certainly mean an increase in funds, but it is one of those things that we should be providing for this sector of our society.

Dr. BELL. Yes. Perhaps we should not settle the issue on the basis of cost savings. There will be savings as a result of the changes you mention, and likely some elderly will, in many cases, be served better at home. In fact, my 1971 study points out that close to 90 percent of the elderly living at home who are impaired want to remain at home.

Senator CHILES. I don't think we can settle on the basis of cost, but there is the issue that we cannot ignore, and that is the fact that older people prefer largely to remain at home. I think the whole bias of our current medicaid program is to break up the family and to force people into nursing homes. I do not feel, and I have not observed in any study that I have ever read, that older people are shuffled off into nursing homes by families at the drop of a hat. I think that in most cases that is the solution of last resort, not the solution of first resort, and the

family does this reluctantly and finds that there is no other way to go. So, I share your view that we can at some point begin to address the moral issue of retaining the family integrity and providing the kind of service that older people who need long-term care require.

We heard from older citizens as well, and we found that people who had given up because there was nothing for them to do, for example, were brought into the green thumb program, or the RSVP programs, or one of these other programs, where they could help, in turn, with the elderly and their whole attitudes changed completely. They now had something meaningful to do. We heard of people that had lost a loved one, and they had perhaps retired in an area and had no friends, and were now coming into a congregate meal center. Now, that changes everything, their entire attitude, and certainly those people are not going to be senility victims as soon, or perhaps just won't be, because they will continue to be able to live in their homes. I think that is tremendously important.

Mr. Carter, how many nursing homes would you say have programs that are developing something with a potential for the people, like you are doing in your Advent Christian Home?

Mr. CARTER. I don't have any figures. The Special Committee on Aging report said that only something like 5 percent were doing a good job in the Nation. I don't know what criteria they used.

Senator CHILES. Are there stumbling blocks in the Federal regulations that work against this or not?

Mr. CARTER. My honest opinion is this, that to take care of a person with the funds that are available through medicine, you have to keep them in a state where they will cause you the least amount of trouble. That means oversedating them, keeping them out of the way, inactive, and unfortunately, this is the case in most nursing homes, whereas if you are really trying to help an older person, you try to get him off of medication, you try to get him out of bed, you try to keep him up and active, to keep his blood circulating, and to keep his mind clear. If you do this, then you can develop meaningful activity programs, because they will not be zonked on medication to the point they cannot do anything.

There are plenty of activity programs that I have observed where people are sitting in a room with a television blaring, but few are involved because they are in a twilight zone. This is too much the case in most nursing homes.

GERIATRIC NURSE PRACTITIONER CLINICS

Senator CHILES. I note that Florida has passed a bill that now allows physician assistants and nurse practitioners to practice in nursing home based geriatric nurse clinics. I know this is fairly new. Could you give us any results on this legislation?

Mr. RISH. We don't have any track record on it yet; it is too new, Senator. We brought it into areas where there were large congregations of these people living together, where they should have had the medical service. It was just intolerable, and we proceeded on the basis that maybe a little bit of service with the physician assistants would be better than what we were getting at that time. We were not able to travel out to doctors, and house calls were nil, but we don't have any track record.

Mr. CARTER. The funding is again the crucial thing. The physician's assistant cannot deliver any service unless there is a licensed physician with him supervising it in-house. As I said, we have had a physician's assistant for a year, but I cannot see that it is going to really improve services if a licensed physician has to be present at all times.

Senator CHILES. Congress has recently passed legislation to allow medicare for services of practitioners in health clinics, but I am afraid that authorization was only for rural areas, and you are saying that you have got to have reimbursement in the urban areas as well.

Mr. CARTER. Our program is about as rural as you can find, and we had it interpreted to us last week that we cannot bill for physician's assistant services unless a licensed doctor is with him seeing the patient. That is what I said before.

Senator CHILES. That is the present law, but help is on the way. We have amended that, and I don't know when the new law goes into effect. We will get some information to you. The physician will not have to be present as long as the assistants are under supervision. So he will not have to be present.

Now, if Florida law prohibited that, you would still have problems?

Mr. RISH. Well, this Federal legislation, that I was not aware of until a moment ago, entirely contravenes the Florida legislation, not willy-nilly, but not that the doctor be walking along with him. It was our thinking that there would be a $2 or $5 charge, or what could be afforded, to help sustain it to get the care in there. But within any reasonable constraints, I feel like the Florida Legislature can adjust its statutes to whatever is needed in the area.

Senator CHILES. Dr. Bell.

Dr. BELL. I think part of the problem is that we are concerned about many older people for whom the physician is not critical, as in the case of other forms of care.

EMERGING PROBLEMS

Senator CHILES. Let me point out one of the problems that I see, Billy Joe, and you tell me how Florida is addressing them. As we are building these alternative forms of services, we are seeing—and I held some hearings on this—the so-called not-for-profit, and I say so-called, because at some of the hearings I held, we learned of a man paying himself $30,000, and his wife $20,000, and his daughter so many thousand dollars, and they get themselves nurses, but they set up a nonprofit corporation. That is not my idea of not-for-profit. I think that was the fault, because we had no regulations from the medicare and medicaid provisions. I think maybe we have corrected that now, but as we set up these services, we found again they were paying attendants in hospitals and admission people to refer the patients to them. They were offering services that were not needed. We found where comatose people were getting services that were just ridiculous, they were piling services on. Now it seems that there has to be someone in charge of what will happen when a person—let's say they have gone into a hospital—they have had some kind of an acute illness and they are on their way out. Who determines whether they go into a nursing home? Can they have care at home? If it is going to be at home, who is going to provide it? What kind of care are they going to get?

We find some States—New York, I think, and California—where we are paying the individual practitioner—the individual—to come in and provide service. He could even be a member of the family, in instances. There is no kind of control over these funds. They were coming out of Federal funds and it seems the Federal Government is not going to be able to set up that mechanism, and should not, because that would lend a tremendous bureaucracy, but in some way the States I think are going to have to set up some kind of provisions. The provisions should protect the taxpayers, as to what kind of services are going to be granted, and yet if we are going to allow all these overlapping services we are going to have a lot of people who never find them to start with, so it has to have an outreach with it. We are going to find others that get services that they don't need and perhaps miss services that they do need.

Mr. RISH. Senator, we have the mechanism for that already. And some of the people don't particularly agree with it, but we have the committee to set up now for those who are at least, in the facility, where they classify them according to the type service that they do need, and this has the input from our medical people. What is the committee called? They come through on a periodic visit and do this at the level of care, the committee that establishes and does it on an individual basis.

Now, it would seem to me that very easily we could use that mechanism logistically to make the determination in the first instance, with the help of the family physician.

Dr. BELL. Let me supplement Mr. Rish. When it comes to institutional care, we do have a panoply of services. However, in the community we do not yet have analogous programs, so that we are really faced with two problems. First, how does one determine what the older person at home really needs? That decision is made on a catch-as-catch-can basis; there is no real assessment of individual conditions and needs.

Senator CHILES. I think that is tremendously necessary.

Dr. BELL. Second, suppose we do an assessment and then decide on the usefulness of a certain set of services. These needed services may not exist. We have to have a double-barreled effort to develop a method of social and health assessment by appropriate personnel, and then help to put in place the services that frail elderly need.

EVALUATION AND MONITORING

Senator CHILES. Well, what I think I am reaching for is that as the Federal Government provides—and I think we are going toward providing the programs that will allow the assistants to be there—we want to be sure that we have in place some group with responsibility to do the assessing and the monitoring of these programs, and then the auditing, perhaps, of the programs. If not, then we are going to get into this tremendous waste and tremendous scandal that we have gotten into, where we have opened up some of these programs.

Mr. RISH. We have that. The office of aging and adult services have people starting in the field, starting January 1, which is when the bill that I have passed will be put into effect. Under that bill, the people in the field will go in and interview them and talk to the person

and consult with the doctor, and see what facilities are available in that community, and see if it is a walking stick or hospital bed or some nursing services, or whatever, and they will make that determination on the spot. To the extent that the agency can make that determination, that is the best we can do. That is under HRS.

Dr. BELL. I am glad to hear that. The Federal Council on the Aging has developed a national policy on the elderly, especially those 75 and over, which includes an assessment of the impaired individual. The Senate committee may want to take a look at that report. If you have not seen it, I commend it to your attention.

Senator CHILES. Fine. I would like to forward to you some of the pilot programs that we have had hearings on in different States; Connecticut, I think being one, and some others, and how they set up some of these programs in their pilots. I think that perhaps the mechanism in your bill might be useful. I am not sure that it might need to be broadened to cover all of the services that we are talking about, because it was more relating as to whether they were going to get the funds for the in-home care or family care, but that might well be just the mechanism for something like that that would be needed. I will forward that information to you.

Mr. CARTER. Can I relate my remarks in another dimension on the same problem, levels of care? This is a very difficult thing for the people who work in the nursing homes, primarily because unless you offer all three levels of care in the same facility, you are going to be shifting these people in and out, and if you don't have that level of care, it may mean shifting them across town to a facility that does have it. I have seen people who have died as a result of such moves.

Older people resist change. It is traumatic. They can be alert, and you put them in unfamiliar surroundings and they can become totally confused. Also, the level of the care, as it is now, does not take into consideration how much it costs you to take care of that person. Now, I can put a person in bed who is considered skilled care, and I can get by with far less employees than if I have a person who is custodial and confused and wanders all over the place. I have to almost staff one-on-one for the "wanderer." These levels are primarily for Federal funding purposes, but they play havoc with the nursing home's budget, and really penalize us for trying to rehabilitate the older person. In the end, it is the older person who is being shifted in and out and around who is paying for it—at times with his life.

Senator CHILES. Yes, sir.

Mr. LIPSCOMB. Senator, I just want to address one thing that has been of concern to you and to me ever since I came to Florida, and that is where those people eat those other two meals a day during the week and all three meals on the weekend. Presently, we are trying to work with the Department of Agriculture. As you know, we have a lot of people who live in single rooms and retirement hotels, and this kind of thing. They have no cooking facilities, and therefore under the food stamp regulations, otherwise eligible people are precluded the opportunity of participating in that program because they had nowhere to cook the food.

We are working with the Department of Agriculture, on a prototype basis, to take those people who are eligible for the food stamp

program, which constitutes a good sized number in both the St. Petersburg and Miami area and other parts of the State, to allow them to use food stamps to purchase a meal in a restaurant if it is a family-type restaurant.

Senator CHILES. I think it would be very beneficial. There should be some kind of exchange for those people who have food stamps; they should be able to come in and give that food stamp to a congregate meal center.

Mr. LIPSCOMB. They can do that now, sir.

Senator CHILES. And not have to take all of their meals at one place or another, but be able to come in and exchange that so they can have the companionship, but provide some of their meals at home.

Mr. LIPSCOMB. Presently we are allowing them to use the stamps in a congregate center and allowing them to go to restaurants after the first of the year.

Senator CHILES. I want to thank you all for your testimony. I think it is highly beneficial to us and for our record. We thank you very much.

Mr. RISH. Thank you.

Senator CHILES. Our next panel will be on "Reaction to State Plans and Programs on Alternatives." We have on this panel Margaret Jacks, legislative liaison, Florida Council on Aging, in Tallahassee; Ed Henderson, who is the young man who is a member of the legislative committee, Florida Association of Retired Persons, Tallahassee. He calls himself retired, but I don't believe it.

Eugene Amyx, chairman of the central Florida chapter, National Council of Senior Citizens, Orlando; and Winsor Schmidt, representative, district 2 human rights advocacy committee for the Florida State Hospital at Chattahoochee; assistant professor, department of public administration; and research associate, institute for social research, Florida State University, Tallahassee. He is trying to get people out of our State institutions who don't need to be there.

I recognize John Clark—I think he is still with us, John is representing Congressman Fuqua. John, we are delighted to have you attend our hearings here.

I want to ask all of you if you will hold your statements down so we will have time for questions and discussion. All of your statements will be included in full in our record. I am just afraid that time is going to catch up with us.

Margaret, do you want to start off?

PANEL ON REACTION TO STATE PLANS AND PROGRAMS ON ALTERNATIVES

STATEMENT OF MARGARET H. JACKS, LEGISLATIVE LIAISON, FLORIDA COUNCIL ON AGING, TALLAHASSEE, FLA.

Ms. JACKS. I think the comments here have certainly raised a lot of questions. I do want to commend you also, if I may, for the statement that I have had shared with me, which you and Senator Church made, with respect to reorganizing HEW and the need for doing something about pooling what has been a very splintered approach to planning for services for the elderly.

Senator CHILES. We have been trying to.

Ms. JACKS. I think your suggested changes make more sense than the present administrative structure.

Senator CHILES. I have been trying, every time we hold a hearing, to put them on the spot and find out who the head of the ship was, and they now tell us that they are going to define that for us; if they do, maybe we will make a little progress.

Ms. JACKS. This is the most hopeful thing that I have heard about in a long time, because it seems to me that our problem, certainly here in Florida, has been one of a splintered approach, both to the development of services and to the funding of services. It is very clear that we moved originally, as you and some of the others commented earlier, from thinking that institutional care was the only answer to needed care, to a plan which placed greater emphasis on care in the home, and which moved us almost entirely away from institutionalization. This switch was motivated, in large measure, by the fear that people would be mistreated, would not be taken care of adequately in institutions. It assumed, somewhat naively, that everybody could be taken care of at home. As a result, we moved to the development of home care programs as a major priority.

"HALF TRUTHS"

It seems to me that there are only half truths in both of these patterns of care. Certainly, some people are eventually going to need institutional care. You have to recognize that this is not a very pleasant assumption, for institutional care makes us think about death, and frequently we react to placement in an institution as being one step closer to the end. We all reject the idea of having to go from our homes into an institution, knowing full well that quite often if we go to a hospital and then to a nursing home we are probably not going to go back home. I think that is the fear of many older people. It is also the fear of younger people, but they don't want to think about it.

An additional basis for our rejection is the high cost of institutional care and the highly publicized incidents of poor care in some—but certainly not all—nursing homes. Some homes provide excellent care, but there is always the specter of mistreatment and neglect as a possibility when institutional care is required.

We who work with the elderly, or are older ourselves, are worried about this. Many older people are also worried about the cost of medical care, because on a fixed income an extended illness or a catastrophic illness can eat up reserves, if such reserves exist. Those people that are on a fixed income, even those people with fairly good resources, are fearful of what an extended long-term illness will do to their resources. They are concerned as to whether or not they are going to be able to continue to be independent physically and economically.

They do want to remain in their homes as long as they can.

As far as the home care services that we have developed in this Nation and in Florida, I am not at all sure that they are any cheaper than institutional care. If you are talking about just the economics of how we are going to plan for the care of older people, good home care with all of the services—homemaker services, home-delivered meals, transportation, comprehensive medical care, visiting nurse service,

and all of the other services they may need—is very costly. So I do not think that care in the patient's own home is going to save us a lot of money.

Senator CHILES. I agree.

Ms. JACKS. I think to assume that it is, without more definitive hard data, to stick our heads in the sand. It is many times the most humane thing for the older person, and at least it gives the older person a choice——

Senator CHILES. It is a better utilization of the money we are going to spend.

Ms. JACKS. And it does provide for the older person an opportunity to make decisions about his own well-being and where he wants to live, if there are these resources developed in the community.

Senator CHILES. Right.

OPPORTUNITY TO PAY FOR SERVICES

Ms. JACKS. Now, I think that one of the things—and this may not be a very popular remark, but I must say it—I am concerned about people with low income, but I don't think that just the low income need services, and I am afraid that in our concern for how we are going to pay for services in this Nation of ours, we have tended to say we are going to provide all these services for low-income elderly, forgetting that many of the elderly who have money cannot get services because the services are not provided for them.

Senator CHILES. They cannot even be purchased

Ms. JACKS. That is right. I hope that in this reorganization that you are talking about, at the Federal level, and at the State level, we can do something toward recognizing the potential in a fee system that would provide the older person with an opportunity to know how much the service costs. Let him participate in determining how much of that cost he is able to pay, and then give him the opportuntiy of paying for his care, if he can do so, and with the Government stepping in at all levels, to assist those people who could not provide for their own care.

I know this concept is not popular in some areas, but if an older person who has money needs services, and the service has not been developed in that community in a way which let him do this, then it is not available to him. I think this is nothing short of criminal.

Senator CHILES. Under those circumstances you are better off to be poor.

Ms. JACKS. Yes.

Senator CHILES. Because then the service would be provided.

Ms. JACKS. Yes, you are better off because if you cannot get the service—you cannot buy it—you are out of luck.

Senator CHILES. Right.

Ms. JACKS. I think so many times, when these more affluent people in Florida move into a condominium, they currently have money enough to get along, but they also, inside of 7 or 8 years, are likely to be in need of services even though they may still be able to pay for care. Where can they turn to in the community? I don't know. Services for them just don't exist.

There are just one or two other things that I would like to emphasize on what has been said here today. I think they are very important. First, and perhaps most important, is that we are going to have to do something about preventive care so that we can hopefully keep people from having to reach out for home care services or to eventually go into an institution. Maybe they will have to eventually, but at least we can postpone this. This means involving, to a large extent, the personnel that provide services for older people—social service, group workers, and medical personnel. I am so delighted with what Pomeroy Carter is doing down at the Advent Christian Home, involving the medical personnel at the University of Florida, so they will know something about how to deal with older people.

"Professionals Not Prepared"

I am sorry to say—if there are any doctors here, I apologize for being critical—but I must say that in large measure physicians do not go into their profession prepared to work with older people, and as a result they don't really understand what they are dealing with. They do not offer the preventive consultation and care that should be given. Medicine and pills seems to be the answer rather than trying to help the community and the older person to develop and make use of a variety of services that would maintain that person's health for a longer period of time, both his physical health and his mental health. The social workers need to have better training in how to deal with older people, so that they will understand that older people sometimes need to move a little more slowly in presenting their problem, they need to have someone with a sympathetic ear who will listen to what they need to say and who understands their fears. For example, older people fear that they will become ill, they fear that they will be dependent. They don't want to be dependent. They want to be independent. They want to make decisions about their own well-being as long as they can, and if people who work with them can understand this and give them the opportunity to work together, rather than the social worker being the do-gooder—if I may use that expression—and perhaps from very good motives, wanting to do things for the older person, rather than letting the older person make the decision and do things for themselves. So your doctors and social workers, and all the other professionals, I think, must learn to be aware of what they are dealing with in working with older people and open the doors to continued involvement and preventive care and activities for them. Unless we can do this, I don't think we are going to achieve community care.

The other thing that I think is tremendously important, I believe it was said earlier, but I would like to emphasize it, and that is that we have got to do something about the splintered approach to service delivery. It is too bad that in this Nation of ours, when older persons need help they can't find out what is in the community in the way of needed services, and when they do find out, through an information and referral service, they have to go to 16 different places and file as many application forms, frequently one for each service they need.

Senator Chiles. Right.

Ms. JACKS. They must repeat, over and over and over, what their problems are, and be embarrassed many times in having to admit dependency, rather than having this service provided through a one-stop center, as Bentley Lipscomb mentioned. I think this is of paramount importance, so that the older person can go to one agency, can receive help in knowing what is available, can tell his story once, a plan for services and assistance can be arranged, and then someone helps to follow through on the provision of appropriate services.

I know I have rambled, but I just wanted to emphasize these things that were said earlier this morning because it seems to me that these are the things that we must be concerned about—the well-being of the individual, not aging per se, but each older person. To achieve this, we have to look at these points I have reinforced.

Senator CHILES. Thank you.

Ms. JACKS. Thank you.

[The prepared statement of Ms. Jacks follows:]

PREPARED STATEMENT OF MARGARET H. JACKS

Not all older people need services, nor are all of the elderly in need of financial aid. There are many among the elderly who have made the transition from middle age to the maturity of the later years and the freedom of retirement with few problems. Most of those fortunate individuals have been able, during their working years to earn and preserve resources with which to meet economic needs when earning years are terminated.

Some elderly formerly worked for concerns which provide adequate pensions for retired employees. Other concerns have shared with employees the opportunity to amass reserves through the purchase of company stock or through supplemental savings programs to build reserves. Other elderly have, on their own initiative, been able to follow through on a sound savings program, planned to accumulate retirement reserves.

Social security provides a basic plan to which other pensions or sources of income after retirement can be added. Social security alone is not sufficient to meet total economic and medical needs for most older people. Only when added to other retirement income is the total sufficient to provide for a comfortable life style which allows the individual to purchase needed services. But for those who have not been so fortunate as to have other retirement income and for those who, while working to support themselves and their family and to educate their children, have been unable to accumulate reserves, retirement on social security alone is usually accompanied by fear of want, if not actual lack of the necessities of life.

The economic situation in which the retiree finds himself, either affluent or with limited income and resources, may be drastically affected by the complication of severe or prolonged bouts of illness, especially if there is a residual condition which affects the mobility and general ability of the individual to function independently. With the escalating cost of medical care, resources can be reduced or completely eroded in a short time. As a result, just at the time when the individual begins to need a variety of services to augment reduced functional capacity, the ability to purchase such services is limited by a reduction in income and resources.

Another generally negative factor in the provision of services to the elderly is the slowness with which these ancillary services for the disabled elderly are being developed in American communities. Possibly because of a national self-denial of the inevitable onslaught of old age, we as a Nation have tended, in an ostrich-like manner, to deny the need of such services for the elderly other than institutional care. As a result, State hospitals for the mentally ill have had many older nonpsychotic patients admitted to the institution, and nursing homes, some with good and some with not so good standards have been used inappropriately for the care of many persons. These include persons who could have remained in less restrictive, more appropriate, living arrangements in their own home or in a protective living situation if services to augment their ability to function had been available in the community.

Also, in many communities, where some services do exist, there is a lack of information and referral services to inform the general public, including the elderly and his relatives, as to what services exist, how they can help, their eligibility requirements, and how to apply. This void, this lack of knowledge about services and their availability, has restricted the elderly and his relatives in making maximum use of such resources to plan for care, out of and in place of, unnecessary institutional placement.

In America, there has also developed a well-placed, but sometimes too narrow concern, for the well-being of needy individuals, particularly the low-income elderly people, which has led us to a public policy of limiting the development and availability of service resources to those which meet the needs of the elderly poor. This restriction loses sight of the fact that affluent elderly may, and frequently do, need those same services, but find their income a barrier to their receipt of such services. This must and should be changed to a policy which makes all services available to all elderly with a fee system which informs the individual, seeking such services, as to the cost of the services and allows him to pay in relation to his stated income with the cost of care to indigent individuals being met through public funds.

The services which have been identified as being of greatest benefit to the older person with reduced capacity to function in the activities of daily living are: Homemaker services, visiting nurse service, transportation (portal to portal, in specially designed vehicles), telephone reassurance, home-delivered meals, meals served at congregate sites, physical therapy, etc. These, of course, should be available in addition to medical care, placement for care in a medical facility (hospital or skilled nursing home), or care in a protected living facility (foster home, home for the aged, etc.), as appropriate to the individual's particular needs. Unfortunately, this array of home care, medical care, and appropriate levels of institutional care are not available in most communities in Florida, nor are the numbers of service agencies or appropriate institutions, where such exist, sufficient to meet the demand for such services.

An additional, but equally limiting factor in developing a plan of care for the disabled elderly is the splintered administrative approach to service delivery in most communities. Each agency usually has its own eligibility criteria, application process, and procedures requiring the filing of a unique application form. As a result, it is not infrequent that an older person must go from one agency to another, filing similar, if not identical information in each, going through the traumatic admission of being dependent physically and economically, over and over. Such would be the experience of a person needing homemaker service from a title XX (social security) project, home-delivered meals from a title III (Older Americans Act) project, service of a visiting nurse from Public Health, etc. With the knowledge of what is needed or available obscured by lack of a good information and referral service, the elderly often find it impossible to consider alternatives to institutional care.

When institutional care is appropriate, the choice of which institution, or what level of care is needed, is frequently complicated by incomplete cooperation of the doctor in charge of the patient's medical care, who may himself not be completely familiar with community resources. With proper attention to a complete diagnosis and alternate means of care, drugs may be reduced for more constructive programs of exercise and participation to overcome depression and inactivity. Home services can be prescribed appropriately to avoid unnecessary institutionalization, but only if the physician is attuned to the special needs and problems of the elderly which may require more time for discussion of symptoms, a sympathetic listening to sometimes prolonged explanation of symptoms, a possible lack of hearing, which may require repetition of information giving, and a general understanding of services available in the community which can be used to complement the medical care regime he is prescribing. It is the physician who should be participating in the development of institutions providing various levels of care. When an older person can no longer live in his home, a foster home or a home for the aged which provides a semi-independent life style should be available for consideration as a solution to the question of care. The community should not only foster the development of such resources, but provide a licensure procedure which assures safety, cleanliness, adequate nutrition and well-prepared meals, personal help in dressing, ambulation and bathing. Counseling on personal problems and medical supervision to identify possible symptoms of developing illness as well as leisure time activities to preserve mental and physical functioning should be provided in such facilities.

When acute illness exists, the spectrum of medical care, including physicians care, clinics for routine followup, hospital and skilled nursing home care as required, should be available to the individual at a cost which he can pay or provided out of public funds. Such services, particularly hospital and nursing home care, should be administered in a way which promotes return to the patient's home when his condition permits this, with rehabilitative services provided which are directed toward this goal.

Thus there are a number of subgoals in the goal of developing a community care program in any community if it is to provide comprehensive services to meet the needs of the elderly at the various stages of development:

(1) The first is the identification of the services needed by the elderly in relation to their loss in ability to function independently, with a view to preservation or rehabilitation of functioning and the development or expansion of such services in the community.

(2) Planning for needed resources to be available to all older people with the cost being met by the individual on a sliding scale, depending on his or her ability to pay, and subsidized out of public funds for the indigent.

(3) Assuring, through the development of sound service delivery methods, that home care services, medical care and appropriate levels of institutional care, are all available in the community with the provision of services directed at preserving the independent functioning of the individual in his own home as long as possible, but also providing for varying levels of care in a variety of settings for short or long periods of time, depending on the person's needs.

(4) An information and referral service which educates the public and the person in need of services, as to what is available in the community, and where to go to obtain the help needed, with assistance given in doing so, if required.

(5) Development of a community service delivery system which makes all services available through a simplified "one-step" application mechanism which assists the individual applying for assistance to identify his or her specific needs, provides a diagnostic process in which the individual partcipates, and through which a plan for the provision of services is established with the filing of a single application form and the processing of one application for all needed services.

This, in summation, is comprehensive community care—an array of social and medical services, including a variety of services to the applicant in his own home if assistance is needed to facilitate his independent functioning in a community setting, with good substitute care offering a variety of levels of care in as many appropriate settings as are needed, to assure the meeting of special physical, mental, emotional, or economic problems. All such services should be available in a simplified delivery system requiring minimum repetition of the application process, with services paid for in respect to the person's evaluation of his ability to meet an established fee system, public funds to be available to meet the cost of care for the indigent.

To achieve this goal, the entire community, particularly existing service delivery agencies which may be a part of the totality of services, must be wholly committed to this end. Such commitment leaves no room for jealously of established prerogatives. Each must be willing to contribute any special knowledge or skills it has and to cooperate to the fullest.

The last—and perhaps the most necessary ingredient—is financial support for the entire program whether it be Federal, State or local funds. Such an integrated program may well receive support from all three levels, as well as from the recipients of service in the form of fees. Imaginative planning and innovative measures will open the door to appropriate use of volunteers, civic groups, clubs, churches, etc., for contributions in cash and in kind.

Florida has gone the distance of passing legislation to initiate such a program. It has not gone that last step of providing adequate funding. Perhaps this hearing will stimulate additional interest and support for its full implementation. Special interest groups—AARP, NAART, the Florida Council on Aging, the National Council for Senior Citizens, the National Congress for Senior Citizens—have expressed their desire to work actively to this end.

I appreciate very much the opportunity afforded me to testify before your committee and commend you for your many years of efforts, concern and well-directed activity on behalf of the well-being of the elderly in our Nation.

Senator CHILES. Ed, do you want to make some remarks?

STATEMENT OF ED HENDERSON, PH. D., MEMBER, LEGISLATIVE COMMITTEE, FLORIDA NATIONAL RETIRED TEACHERS ASSOCIATION, FLORIDA ASSOCIATION OF RETIRED PERSONS, TALLAHASSEE, FLA.

Dr. HENDERSON. This brings back a lot of memories of the days when you were in the Florida Legislature and I was in there struggling with education.

I am not going to repeat a lot that has been said because the thorough discussion in the first group was rather complete. There are just two or three items in connection with it that I want to emphasize.

We were discussing, a little while ago, this care by the physician and the assistant and the nurse. When this bill was passed by the Florida Legislature, the hope was that in these centers, where elderly people would gather, there would be a room or clinic where there would not necessarily be a doctor who would have to charge a fee, nor even a doctor's assistant, but a well trained nurse who could administer to the elderly people in many of the simple problems that they face from day to day. We hope that that is going to be developed without the necessity of having to have the doctor or the doctor's assistant with the necessary fees that they required in order to do that work. We believe that a well-trained nurse put into these activities can do the job adequately for most of the elderly people, and that was the emphasis that we stressed as we were working on this measure in the Legislature of Florida.

We are concerned about another problem that we face over and over. The people that I associate with, most of them simply want to do their own thing; they are in pretty good shape, but a small percentage of people are in trouble, as you know, either because of health which we are discussing mainly this morning, or because of inflation. We hear about so many programs where people are providing things for the elderly people.

A great many of our elderly people have been required to retire. It looks like that is going to be changed a little bit, but 65 comes along and some of these people remain alert mentally and physically. We are hoping that somewhere in the development of this program, further development of it, that we will make use of elderly people in serving elderly people. We have some very interesting programs going on in Florida, as you probably know, among the retired teacher organizations. They have been doing it for years.

The first hearing that we ever had, or the first notice we ever had of one of these day care centers for elderly people, was conducted strictly on a volunteer basis by the retired teachers in St. Petersburg, many years ago. Using the members of that organization, they were able to provide the same kind of services that can be provided in other communities, where younger people are hired to do the work. We would hope that as these programs develop, an increasing number of capable elderly people be used in furnishing the services to our elderly people.

There is another angle that we tried out, I believe, when we had the meeting in St. Petersburg. We had a report from one of the retraining centers, where they offered certain kinds of work—work selected by

the people who were running the activity—and they would offer to elderly people an opportunity to come in. Now, there are certain things that one can get ready to do, but we believe that if the retraining programs can be based upon the aptitudes of the individual, the skills that he has and the abilities that he has, we will find many areas where elderly people can come back into certain types of employment, part time perhaps, because they need the additional funds now, instead of going into the training institutions where existing courses are lined out for them.

I don't think I am going to repeat a lot of what Margaret said, because I had a feeling that between the four people we had on the panel earlier we had a pretty thorough discussion for your committee, and all we want to do is just sit here and have a thought or two, and then say hallelujah.

Senator CHILES. Thank you, Ed. Mr. Amyx.

STATEMENT OF EUGENE R. AMYX, MAITLAND, FLA., CHAIRMAN, CENTRAL FLORIDA CHAPTER, NATIONAL COUNCIL OF SENIOR CITIZENS

Mr. AMYX. Thank you, Senator.

I, too, want to express my thanks for being here. There are some areas that I would like to mention, if I may.

One thing, before I start, I learned last night, in a meeting that I was attending, that I have reached the ultimate goal of being a senior citizen. I was standing in the back row of a crowded room, and a young man in his thirties got up and offered me his seat, so I know I have arrived. I didn't take it.

There are some areas that have been touched on that would be somewhat repetitious, so I will not dwell on them. There are some other areas that I would like to mention.

First of all, let me say I have been retired for 2 years. Previously, I was director of the RSVP program for 2 years, and I have been dealing with older people and their needs and their problems, for several years. I have learned, through conferences and meetings, the No. 1 concern of the elderly is health care. One of the new health problems that has recently arisen, I believe, that should be looked into, is the negative publicity pertaining to social security. This has been an added worry for lots of older people. It needs to be explained, why the negative response that we are getting through the media in so many cases.

PREVENTIVE HEALTH CARE

Some of the areas that have been touched on I would like to repeat. Preventive health care that Margaret mentioned, this is one of the areas that we need, so that older people can find out that they have a problem and something can be done about it before they become so drastically ill. This, of course, would be a huge saving. I might add that the older people I know are not asking for free care, they are asking to pay their share. I would suggest that a sliding scale should be worked out on care of this type.

Another area that concerns us in our area is home health care. I won't dwell on that because it has been covered so well already. I believe that the nutritional classes that have been mentioned, too, have

been a tremendous help in the Orange County area where I live, not only for better health, but for economical reasons as well.

I would suggest that an exercise program suited to the elderly be instigated. It would not only bring better health, but it would bring social contact that is needed in many cases.

Another area that concerns us is a need for counseling. Many older people need help but don't know where to turn. In some areas, they go to an agency where they have employees who cannot relate to them. I am suggesting that these people should have an opportunity to be counseled by their peers, or people who understand their concerns for their ills, for their medicare, insurance, and other areas.

I would suggest also that the transportation for the elderly and the handicapped be looked into more thoroughly. I happen to be on one of the boards in Orange County where we are providing very limited transportation for the handicapped and elderly, but we turned down over 200 a month because we don't have the services to provide more. The primary function of our service is to provide transportation for medical care. So when you cannot serve that many people in a community, then I would hope that this area would be looked into also. The need is great.

Medicare in nursing homes. I heard this morning one of the finest recitations of care that can be offered in nursing homes, and I wish that Mr. Carter were in Orange County.

Another area that concerns me is that many older people are under the assumption that under medicare, if they need to go into a nursing home for skilled care, that they will be accepted. Unfortunately, this is not true. Many counties that I know of, that I have had an opportunity to check on, do not have medicare coverages in nursing homes. I would suggest that we should investigate why this is allowed to happen. I would suggest that the nursing home administrators themselves be asked why the can exclude and refuse certification for medicare patients. Medicaid patients are accepted, but medicare are not.

Excessive Paperwork in Medicare

The answers that I received in looking into this problem is it requires excessive paperwork, and they have a right as individual operators—and most of the nursing homes, I understand 77 percent are privately run—they have a right to reject anyone that they wish. I would suggest, Senator, that the medicare coverage for those who need skilled nursing homes be looked into very seriously.

I would suggest also that many seniors do not want to quit work when they reach mandatory retirement age. I would suggest that many of them would like to continue in some part-time job. I would suggest that many of them, with very little training, and maybe none at all, would be able to serve for many, many years in areas of their interests. I would like to see how this is going to be implemented, and how older people and their skills and expertise will be used. I am suggesting that many, many older people become old and senile simply because they are allowed to, and not encouraged.

While I am on that subject I would like to put in a plug for a new TV program, called "Over Easy," which Hugh Downs is the moderator. It is on the Public Broadcasting Service. HEW sponsors it. I learned by watching it last week, that some of the ideas coming over

this program, "Over Easy," are going to be a tremendous help to older people. I think, from what I have seen, it is a step in the right direction.

I am suggesting that the self-esteem of older people should be encouraged and not be put down. When they are suddenly shunted aside and told, "Now you are no longer useful," this is putting down their self-esteem, and this is the worse possible thing that can happen to an individual. Self-esteem is even more important for an older person than it is for a younger person.

I would also suggest that the adult education classes be enlarged to provide classes of all types, including college level. There is no reason why an older person is not able to learn and continue being active in this life. If they have the opportunity to participate and have an active mind, they are going to be happier individuals. The fact that they have an active mind, I think it is important to remember, is that it doesn't leave time to be thinking about illness or how to be lonely.

Last, it is expected that the percentage of senior citizens in Florida will double by the year 2000, already one of the highest percentages of seniors in the United States of America. We should plan now for that time.

May I suggest that older people should be allowed to help plan for their own lives. I am suggesting that any commission, or any board, that has to do with the needs of the elderly, should have at least one senior person participating on that board. I feel that the older people have this right to govern their own lives, and to be self-sufficient as they want to be, as long as they live.

Thank you, Senator.

Senator CHILES. Thank you.

Professor Schmidt.

STATEMENT OF WINSOR SCHMIDT, REPRESENTATIVE, DISTRICT II HUMAN RIGHTS ADVOCACY COMMITTEE, FLORIDA STATE HOSPITAL, CHATTAHOOCHEE, FLA.

Mr. SCHMIDT. Thank you very much, Senator.

Thank you for inviting me to participate in this discussion. I believe I can contribute some new issues to this discussion, but I will ask that my statement be put into the record.

Senator CHILES. Your statement, in full, will be inserted in the record at this time.

[The prepared statement of Mr. Schmidt follows:]

PREPARED STATEMENT OF WINSOR SCHMIDT

I am a member of the District II Human Rights Advocacy Committee for Florida State Hospital in Chattahoochee, Fla. The Florida Legislation has provided for at least one advocacy committee per district.[1] Each of the four State mental hospitals has a committee associated with it.

The committees have no more than 11 members, including at least two consumers, two providers, two representatives of professional organizations, and one medical or osteopathic physician. The statutory duties of a human rights advocacy committee include: Serving as a third-party mechanism for protecting the constitutional and human rights of clients receiving, investigating, and resolving abuse and rights deprivation reports; reviewing programs and services; and, appealing unresolved complaints, and submitting an annual report, to the Statewide Human Rights Advocacy Committee.

[1] Florida Statute § 20.19 (7) (1975 as amended).

There are 352 geriatric patients at Florida State Hospital who are, and for quite some time, have been identified as, ready for immediate release.[2] These are 352 people in locked wards whom everyone admits are inappropriately placed. Yet they languish there, potential victims of the institutional phenomena of resignation to and dependence upon institutional life, because no one has been able to place them in less restrictive alternative settings.

There are 2,316 persons in the total patient population at Florida State Hospital, approximately the same number as in the year 1922, when Florida's population, of course, was much less. Commentators ranging all the way to Chief Justice Burger have acknowledged the uncertainty of mental illness diagnosis, the tentativeness of professional judgment regarding mental illness; the generally low rate of cure, the fact that many forms of mental illness are not understood, the fact that some forms are untreatable and have no effective therapy, and the recognition that any effective therapy requires patient admission of illness and cooperation with treatment.[3] Given these facts, and the large proportion of involuntary committees, and involuntary or incompetent "voluntary" committees, at Florida State Hospital, it is safe to say that many more than 352 geriatric patients are inappropriately locked up in Florida State Hospital.

Some patient population characteristics are interesting. Of the 352 geriatric patients whom everyone acknowledges are inappropriately in the institution, 140 (39.7 percent) are black, and 249 (70.7 percent) are female. It would be fair to characterize the geriatric population, and probably the total patient population, as being poor, disproportionately black, and disproportionately female (even considering that women live longer).

This situation exists now at Florida State Hospital, the same hospital which 2 years ago compelled the U.S. Supreme Court to declare: "a State cannot constitutionally confine without more [than custodial care?] a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends."[4] In the geriatric population alone at Florida State Hospital, there are at least two individuals who have been recommended as qualified for release to independent living.

The $32,991,516 Florida State Hospital budget consists of $26,284,693 (79.67 percent) in State funds, $3,690,025 (11.18 percent) in Federal funds, and $3,016,798 (9.14 percent) in other funds. "Other" funds are moneys collected in fees from this poor and often involuntary patient population. It is not expected that much more than 60 percent of the $3 million in fees will actually be collected, but when it is, it often consists of Federal program payments to the patients. Of the so-called "State" funds, $2,416,089 consists of match money required of the State to qualify for receipt of certain Federal funds. With these considerations in mind, recalculation suggests that Florida State Hospital's budget is as much as 25 percent ($7,916,192) Federal funds.

The alternatives to public hospital institutionalization in Florida include nursing homes, adult congregate living facilities, and adult foster homes. Each of these alternatives is State licensed, but paid for by the client. In the case of public patient clients, any who are accepted for placement are dependent upon Federal program payments to reimburse the alternative facility operator. For the public mental hospital geriatric patient, even Federal funding is often not enough. The amount of Federal money received by the geriatric patient does not make that patient particularly competitive for an alternative facility opening. The facility operator can get more money for less trouble from other clients.

In any study of the mental health movement, it is apparent that change most readily occurs, and substantial increases in budgetary appropriations are achieved, as a direct result of litigation.[5] The District II Human Rights Advocacy Committee for Florida State Hospital strongly urges the support of S. 1393, a bill permitting the U.S. Attorney General to initiate lawsuits on behalf of institutionalized persons. The right to treatment, the right to the least restrictive alternative treatment, and the right to refuse treatment cannot be realized until they are actually claimed.

Another major breakthrough in the providing of mental care would be requiring private voluntary hospitals to assume the same responsibility for mental

[2] The count of 352 is as of March 1977, the most recent tally available.
[3] See *O'Connor* v. *Donaldson*, 422 U.S. 563, 582–84 (1975).
[4] Id. at 576.
[5] See, e.g., *Wyatt* v. *Stickney*, 325 F. Supp. 781 (M.D. Ala. 1971), 334 F. Supp. 1341 (M.D. Ala. 1971), 334 F. Supp. 373, 387 (M.D. Ala. 1972), *affirmed in part, modified in part sub. nom., Wyatt* v. *Aderholt*, 503 F. 2d 1305 (5th Cir. 1974).

patients as they do for patients with physical illness. This is already happening in at least one metropolitan area as a result of the disaccreditation of the public mental hospital.[6] The State mental health agency involved is agreeing that the hospitals will be required to provide followup care after the mental patients are discharged. To enhance the financing of this followup care, the $122 million being spent on five mental hospitals is being redirected. Florida State Hospital admits that it does not meet minimum staffing requirements, and it is probable that it does not meet many of the minimum constitutional standards for adequate treatment of the mentally ill.[7] Federal encouragement of adequate treatment would be helpful.

Forty percent of the nationwide State mental hospital population has been over age 65.[8] One of every four reported suicides in the United States is committed by a person over 65, even though the elderly represent only 11 percent of the population. The death rate of those over 65 within 30 days of mental hospital admission is 1 out of every 10.[9] With a projected over-age-65 population of 51.5 million by the year 2000, the crisis in mental health care so manifest for the elderly must be alleviated.

Mr. SCHMIDT. All right. Then perhaps I could just respond to some questions. I am here representing the human rights advocacy committee at Florida State Hospital. Our principal concern is that there are 352 geriatric patients at Florida State Hospital who have been identified as waiting for immediate release, and they have been identified for some time now. The reason why they have not been released from this maximum security institution, from these locked wards, is because there are apparently no alternative placement care facilities for these patients.

Senator CHILES. Can you tell us how their status was determined? Was it a result of examination by physicians or psychiatrists? How was it determined now that they are ready for release? How did that come about?

Mr. SCHMIDT. There has been an ongoing evaluation, and the staff has determined that they are eligible for release, but as I suggested, there are no alternative facilities. It is difficult.

Senator CHILES. These are people that don't have any family, or there just is no place for them to go in the community, or no alternative services that can be provided? In other words, they need some help as they go out. I suppose.

Mr. SCHMIDT. That is correct. They may even have a family, but the family may be unwilling to take care of them.

Senator CHILES. Maybe that is why they got put there to start with.

Mr. SCHMIDT. That is true also, Senator.

Senator CHILES. Have you got any breakdown as to what some of their problems are, and what they do need? In other words, what services are not available? Is anyone trying to take these people and say, you know, John Doe needs so and so, and where can he get that? I agree with you, it seems terrible that these people have now been certified that they are ready for release, and yet they are being held there.

Mr. SCHMIDT. At the Florida State Hospital, right now, no one is responsible for actively seeking a location of alternative placement. Apparently, there is a program at Arcadia, in the middle of the State,

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[6] See New York Times, Nov. 15, 1977, p. 1.
[7] See note 5, supra.
[8] See Morris, in Symposium on the Aging Poor, 23 SYR.L.REV. 45, 48 (1972).
[9] Based on Statistical Note, 74 DHEW Pub. No. (HSM) 73-9005 (1973), cited in Stone, The Aging, Mental Health and Law: A System in Transition, 161, 176 (1975). See also, Blenker, Bloom and Nielson, A Research and Demonstration Project of Protective Services, 52 Social Case Work 483, 484 (1971).

to place persons in lesser restrictive alternative facilities. However, in Florida State Hospital, there is no such program to this date, and there has not been for quite some time.

Senator CHILES. So there is no one there that is even trying to find a place to locate these people?

Mr. SCHMIDT. No one has been.

Senator CHILES. No one is given that responsibility?

Mr. SCHMIDT. No one is given the responsibility and is actively performing that responsibility.

Senator CHILES. I believe I have seen some newspaper clippings, announcements by the National Institute of Mental Health, of new programs to develop services as dischargees of State hospitals return to the community. It seems to me that this effort, together with the kind of action that you are calling for, could provide the actual community resources that were needed for their return to the community. How hopeful are you as to the effectiveness of this kind of thing?

Mr. SCHMIDT. I am hopeful, Senator, but at most it is a start.

Senator CHILES. I would like to put in the record at this point the newspaper article on these demonstration programs.

[The newspaper article follows:]

[From the Washington Post, Nov. 16, 1977]

COMMUNITY SUPPORT PROGRAM SET TO AID EX-MENTAL PATIENTS

(By Victor Cohn)

In 1965 there were 600,000 patients in the Nation's public and private mental hospitals. Today, in one of the most dramatic achievements of modern mental care, there are 190,000.

But thousands of the formerly hospitalized, as the National Institute of Mental Health acknowledges, "live isolated, marginal lives, wandering city streets and languishing" in boarding homes, cheap, rundown "welfare hotels," and drab nursing homes for lack of better places to go.

Dr. Bertrand S. Brown, NIMH Director, announced what he termed a start yesterday on attacking the problem: $3.5 million in first-year contracts to 16 States to plan or begin "community support programs" to help these men and women lead better lives.

"They are the walking wounded of the mind," he told a news conference. He explained how new drugs and new community programs—psychiatric wards in community hospitals and community mental health centers— emptied the public mental hospitals starting in the 1950's. He said court rulings all over the country are continuing the process—for example, the decision in the District of Columbia ordering St. Elizabeth's Hospital to discharge 1,100 of its 3,000 patients to less restrictive living arrangements.

The problem, Brown said, is that it may be possible to find a bed someplace for the discharged patient but not the "full range of life-supporting services"—medicine, housing, nutrition and others—that were provided by the large public hospital, whatever its shortcomings.

In key communities in the 16 States, he said, a "core service agency"—a hospital, mental health center, rehabilitation center or some other organization—will "take the lead" in mobilizing Federal, State, local, and private facilities of many types to provide services, including job help, recreation and better housing, as well as continuing medical attention.

"There are many such local projects already," Judith Turner, head of NIMH's Community Support section, reported. She said one in southwest Denver has succeeded in drastically reducing ex-mental patients' relapse and rehospitalization rates.

Peter Schuck, Assistant Secretary of Health, Education, and Welfare for Planning and Evaluation, will head an HEW task force to work with HEW and other Federal agencies to bring other programs—housing, medicare, medicaid, social security, and others—to bear on the problem.

States selected for contracts are Alabama, Arizona, California, Colorado, Florida, Georgia, Maine, Michigan, Minnesota, Missouri, Montana, New Jersey, New York, Ohio, Oregon, and Texas. A Maryland proposal could be funded next year, HEW officials said.

Mr. SCHMIDT. I am hopeful, but at most, I can say it is a start. Apparently $3.5 million in first-year contracts have been let out to 16 States. Florida happens to be one of those States. Unfortunately, the amount that Florida is getting from that budget is $262,000 for 1 year. This is reminiscent of another program for the developmentally disabled. It was funded at $100,000 per year, for 5 years, to perform advocacy services for approximately 300,000 clients. As I say, it is a start, but it is not near enough, Senator.

Senator CHILES. I notice Florida is now experimenting with a special gerontology community mental health project in some 11 counties. I did amend the fiscal year 1977 Labor-HEW supplemental appropriations bill that provided $2 million for the Center for Studies of Mental Health and Aging. That is, again, just probably a drop in the bucket of what is needed, but we did provide some funds there.

Mr. SCHMIDT. That is much appreciated. Unfortunately, I am not sure it is being felt in north Florida, where the largest State mental institution happens to be located.

Senator CHILES. I am sorry that we have lost some of our State people from the panel. They had to leave. It would seem to me that someone should be designated in the hospital at Chattahoochee, that that would be their responsibility, because it seems strange that you certify, or you have one end of the hospital, the medical people, certifying that these people can leave, and yet they are still there, and there is no one to try to help get them out in the community.

Ms. JACKS. May I comment on this, Senator Chiles?

Senator CHILES. Yes.

Ms. JACKS. Bentley is coming back, so let him speak, because I would rather he speak on this point.

Senator CHILES. Professor Schmidt was pointing out the number of, some 352 elderly people, that have been certified for release from the mental institution at Chattahoochee, but they are not back in the community because no one is trying—there are no services, they need some services. Is there someone with responsibility, at least trying, to find how we get these people back in the community?

Mr. LIPSCOMB. That, of course, has been the main concern, Senator Chiles. We are reluctant to take people out of the institution which is providing personal and medical care and place them back in the community where there is no medical service, no dental care, no home delivered or congregate meals, no personal care like Mr. Carter mentioned earlier. I recently came back from the G. Pierce Wood Hospital, located in the central part of the State, which is more overcrowded than Chattahoochee, with about 1,200 people, where it was originally designed for some 900 people. We have formed a task force down there, that is made up of the hospital administration and the service networks in that area, to try to develop plans for moving out 300 people by the first of June. If we could put into place some of the community support services that I mentioned in my comments earlier this morning, then we would hopefully be able to move these people

out of these institutions. But I think that it would be criminal, at this point, to take them out of the institution where they are at least receiving minimal care and place them back in the community where they would likely perish for lack of any support services.

Senator CHILES. I understand that we have a hiatus or a vacancy in some of those services that should be available, but I think it is important to know that someone is at least trying to determine whether there are places that they could go, are there areas in which they could go so that they could be released, and then if we can find out if those services are not being provided, I think that would even help us in making our record, as we go in to amend the Older Americans Act, and as we try to determine what other steps we need to provide in this long-term care.

Mr. LIPSCOMB. I think one of the things you have already done, Senator Chiles, is going to produce, I feel, some breaking up of this hiatus. Mr. Derzon has now indicated that he is going to have some folks in his administration look at the issue of long-term care and plan accordingly. At least somebody is working on this particular area.

In assessing the Chattahoochee group, as well as the G. Pierce Wood group, between 80 and 90 percent of those individuals who have been identified as being ready for release, it appears that they will need to go in another form of institutional care; that is, the nursing home facility as opposd to being released into the community at large. The whole issue of certificate of need and the health planning area are things that I think that the States as well as the Federal Government have got to address.

We have a surplus of nursing home beds in many areas of the State, but that surplus will not accept medicaid patients, for some of the reasons that Mr. Carter mentioned earlier, such as the difference between actual costs of patient care and what medicaid will pay. Unless we can up the percentage of beds in nursing homes that will take nursing home patients on medicaid, then we are at a loss as to where we put these people. For instance, the Fort Meyers and Naples area is one of the fastest growing areas of the State, in terms of elderly population. The waiting list down there now is approximately 3 months to get into a skilled nursing facility or an intermediate facility, and some people who have to go in now are being placed above Crystal River which is all the way past the middle of the State. So it is a dilemma that we need to continue working on and trying to resolve in terms of identifying and developing facilities in the community where these persons can be moved from mental health institutions back into the community without killing them at the same time.

[Subsequent to the hearing, Winsor Schmidt submitted an additional statement, which follows:]

Mr. Lipscomb's response to my abbreviated statement was fine, except that his deinstitutionalization program is active in Arcadia, not Florida State Hospital in Chattahoochee. Although the possible consequences of "dumping" into the community may sometimes be unfortunate, "warehousing" in public mental institutions is not only worse, but also violative of the least restrictive alternative standard, and Supreme Court mandate in *O'Connor* v. *Donaldson* to release those nondangerous persons capable of surviving in the community. The public mental hospital should be the last resort, not the first resort.

These concerns are equally applicable to Victor Cohn's Washington Post article. New drugs may have encouraged deinstitutionalization in the 1950's, but the decrease since 1965, when there has been no comparable new drug development, is almost wholly attributable to judicial orders and new community programs. This is why passage of S. 1393, permitting the U.S. Attorney General to initiate lawsuits on behalf of institutionalized persons, is so important.

Also endorsable are the Comptroller General's recent recommendations to the Congress in the report on returning the mentally disabled to the community: Government needs to do more—

"(1) Congress should designate a committee in each House to monitor all Federal efforts in community placement of the mentally disabled for facilitation of Federal agency liaison with the States and between themselves.

"(2) Congress should require developmental disabilities programs to concentrate on coordinating local activities.

"(3) Amend the Social Security Act to increase the outpatient mental health services available under medicare.

"(4) Congress should consolidate funds earmarked for mental health under the special health revenue sharing and the community mental health center programs into a formula grant to State mental health agencies.

"(5) Congress should consider additional legislation to help Federal, State, and local agencies provide more job training and placement services to the severely mentally disabled who have particular disadvantages in the job market."

See, also, the recommendations in the preliminary report to the President from the President's Commission on Mental Health, September 1, 1977.

HEW Focal Point on Long-Term Care

Senator Chiles. Mr. Lipscomb, you referred to the statement from Robert Derzon, who is the Administrator of the Health Care Financing Administration. He has informed our committee that his agency has been assigned the major responsibility in developing the Department's policy on supportive services intended to prevent or postpone institutional care. That is what we have been trying to get out of the Department for a good while, as to who was going to be in charge. We had conflicting responsibility. He has also, at our repeated request now, given us a timetable for future HEW actions that they hope to accomplish.

I would like to put a copy of his statement, together with a copy of the timetable, in the record. He is talking about a home health analysis by December 1978. He would provide us with a plan on national health insurance and long-term care by March 1978, development and testing of major structural reforms by December 1978 through 1982, and an analysis of program benefits by August 1978. We certainly hope that they will be able to meet these timetables but at least we now have some guideposts of the timetable the administration hopes to accomplish. We hope they will be able to meet that, too.

[The documents referred to follow:]

Department of Health, Education, and Welfare,
Health Care Financing Administration,
Washington, D.C., October 27, 1977.

Hon. Lawton Chiles,
U.S. Senate, Washington, D.C.

Dear Senator Chiles: As promised during the hearings before your committee on alternatives in institutional care, I am transmitting our timetable for the development of long-term care policies over the next year.

Secretary Califano has a deep commitment to improving the delivery of long-term care services to the aged and disabled and considers this work a high priority. He has assigned to the Health Care Financing Administration the lead in developing the Department's long-term care policies. This effort will involve

several components of HEW, but the work will be closely coordinated and will be aimed at eliminating any inconsistencies among our programs. In particular, we will work closely with the Public Health Service on all health-related policy matters.

I have assigned the responsibility for directing and coordinating the work to the Office of Policy, Planning, and Research in HCFA. Within the next year we plan to begin resolution of some of the problems of concern to you and your committee. The actual products promised are likely to vary from full reports with recommendations, as in home health care, to shorter analyses of more narrowly defined issues.

The attached timetable shows some of our planned work during the next year. It should be recognized, however, that the issues are sufficiently complex to require analyses beyond the scope of one year. There is general consensus the merit of health and support services to keep the aged and disabled in their communities.

The issues now confronting us are those of financial resources, incentives, and administrative feasibility of different service delivery methods necessary to provide care that is of high quality and at the same time is economically feasible. These are the difficult but necessary issues we must address as we contemplate changes in the structure of public long-term care programs.

In addition to the work outlined in the timetable, there is a substantial amount of analysis that has been underway for some time. Some of this will be completed within the next year, while others will be on a longer range basis.

Periodic reports of our progress will be provided to your staff, and we welcome their suggestions and assistance.

Sincerely,

ROBERT A. DERZON, *Administrator.*

[Attachment]

TIMETABLE.—DEVELOPMENT OF LONG-TERM CARE POLICIES

(1) *Home health analysis.*—December 1978.

This will be a major effort conforming essentially to the provision for a full study of home health services outlined in H.R. 3, the Medicare and Medicaid Fraud and Abuse Act. Major areas to be studied include availability administration, provision, reimbursement, and cost of home health and other in-home services under titles XVIII, XIX, and XX. Interprogram coordination issues, utilization control, and prevention of fraud and abuse are other issues that will be included in our report to Congress.

(2) *National health insurance and long-term care.*—March 1978.

The administration plans to propose national health insurance legislation early in 1978. An integral issue in NHI is how long-term care services should be treated. This analyses has already begun and will continue as plans for the overall proposal are formulated.

(3) *Development and testing of major structural reforms.*—Development, December 1978; Project Implementation through 1982.

In order to eliminate problems of fragmentation and institutional biases in long-term care, we plan to develop and test major alternative service delivery and financing methods. The general goals of these efforts, which will be of a long-range nature, will be to test models for coordinating services and providing a community-based continuum of care for the population at risk. We will test various service combinations, organizational and administrative arrangements, and types of financing. Developmental work will take place during the next year, and demonstrations should run for 3 years after that. We believe that such a comprehensive and long-range effort is necessary in order to answer questions about needs for and costs of services under differing organizational and financing arrangements.

(4) *Analysis of program benefits.*—August 1978.

During the next year we will undertake analyses of the results of the section 222 experiments and other relevant data to assess the feasibility of including such benefits as homemaker and day care services in medicare and medicaid. We will also continue our current activities aimed at improving the provision and assessment of the quality of institutional and noninstitutional long-term care, including the analysis or reimbursement issues, incentives, and greater involvement of consumers, providers, and health planners.

Senator CHILES. Professor Schmidt, we thank you for the work that you have done in this area. I hope that you will continue to keep us informed of what you see is happening, and we will see what we can do about trying to move the Federal Government. I think that makes such an emphasis on the need for having programs in place. To think that people have been institutionalized in a mental institution and now have been certified for the longest time that they don't need to be there. The fact that they continue to be held there is just an indictment of the way we are giving this care, and I think we have to do something about it.

I thank you all very much for your testimony today and for adding to our record.

Mr. HENDERSON. Senator, there is one problem that has been presented to me, over and over, by a number of people that does not deal with the same subject that you have this morning, but we seem to find quite a number of widows who are drawing pensions from the service of their husbands to the Nation in time of war, and they have this very difficult problem that when social security is raised, supposedly, it is to add some other income to these people, but when the social security amount is increased, the pension is cut down, so that really these people are getting no increase from the increase in social security at all.

Senator CHILES. Yes, sir. We have run into that and a number of us have attempted to add that as an amendment so that they would not be cut back. Those pension programs are based strictly on the basis of income, and as you get additional income, then it cuts back on the pension program. But you are right that they don't receive the benefit, and inflation, I think, does eat it up completely.

Mr. HENDERSON. Well, if there is anything in the world that you folks can do. To take a widow now, who is drawing a pension from a man who served the Nation, and then simply because some additional social security money comes in, the pension is cut back on the service that the man rendered, that seems to me totally unfair, and we hope that something can be done about it.

Senator CHILES. Well, there was an amendment to the—staff has just reminded me that the McIntyre amendment was placed on the new social security bill that just passed the Senate, and it would say that there would not be a cutback. That is not in the House provision so I don't know whether that will be held through the conference or not, but it was in the Senate side.

Thank you all for your attendance today.

We have a few minutes left and I understand we have some people that are in the audience, some of our senior citizens, who have something to say to the committee. We will be glad to hear from you for a few minutes.

Let me just mention that we also have some sheets on the table in the lobby, the pink sheet, and if for some reason you aren't able to testify, or if you don't want to stand up and testify, I hope you will fill out one of these sheets because we would like to include those in our record. We have got a mike over here. I am going to be able to stay about 15 minutes and then I am going to have to go to the airport, but maybe Mr. Oriol, the staff director, could stay just a little bit longer if there are other people. So those of you who would like to make comments, we would be glad to hear from you.

STATEMENT OF ELLEN KERR, TALLAHASSEE, FLA.

Ms. KERR. I am a resident of the building—have been for the last 6 years.

A point was made by several of the speakers, particularly by Ms. Jacks, which seems important to me. Can't you, Senator Chiles, won't you prod and push the medical profession and the AMA to getting more deeply involved in preventive medicine?

Senator CHILES. Yes, ma'am. I have been trying to do that, and one way I have been trying to do that is in the Appropriations Committee, of which I am a member of the Subcommittee on HEW, in trying to fund medical schools in a way that sees that we are going to have a better mix of people that will be involved in the community practice—general practitioners we used to call these people—and in the geriatric practice, as opposed to just a few specializations and just the treatment of the traumatic illnesses, as opposed to the chronic illness.

We have been trying through our financing provisions to do that, and I will continue to make efforts. I think it is very, very necessary.

Ms. KERR. Would it be possible to incorporate that in the services of the centers for the elderly, the municipal centers?

Senator CHILES. Well, yes, it is possible, but again we get into the—a lot of this is not funding and that is where we are trying to provide nurses and physician assistants who could be available because in many instances they could be helpful in giving this preventive care. You would not have to have a physician present all the time. What we are talking about, of course, is the expense.

Ms. KERR. I should live so long that I will see it.

Senator CHILES. Well, I hope you will.

Ms. KERR. Thank you.

Senator CHILES. Thank you, ma'am.

Ms. KERR. One other point, please. We who live in this building have enjoyed its facilities, its comforts and its conveniences very much, but there is a crying need for a second building. I think all of us who live here are aware of the need for a building that will provide the services for people when they become old and are unable to care for themselves.

Senator CHILES. That need exists all over Florida and all over our country.

Ms. KERR. Yes; don't forget it.

Senator CHILES. Yes, ma'am.

Ms. KERR. Thank you.

Senator CHILES. Yes, ma'am.

STATEMENT OF EUNICE P. ANDERSON, TALLAHASSEE, FLA.

Ms. ANDERSON. Senator Chiles, all morning we have talked about money. We have got brains enough to handle any problem. I have been working in Dade County for 40 years on a volunteer program which includes aging—I would like to know how we can get you folks in Washington to cut this inflation without having to go to war? It seems that we always are in war when we are not inflated. That is because, of course, of employment.

Now, I would like to see some of the junkets that some of these folks are taking—I read the paper and I see all this money squandered on all this useless stuff—and if we don't stop and if there is no hope for us older people, you can call it whatever you will, but we have to talk about it this morning, but nobody majored in cutting inflation. I think it is very basic to the whole packet of what we are talking about; which is, money to do these things. I would like to have some thought on that. Do you have a good idea?

Senator CHILES. Well, I wish I could say that I had an answer to that, but one of the things, of course, we are continually trying to battle with is inflation, and you are right, it is one of the greatest problems that we have. Part of it is caused by too much Government spending.

Ms. ANDERSON. Well, amen. That is what I am going to tell you.

Senator CHILES. Well, there are people who say if you cut out the programs for older Americans, you would not spend as much money, and there are other people, depending on what program you like——

Ms. ANDERSON. But you have a lot of pet programs that are just boondoggling.

Senator CHILES. One man's pet program is another man's necessity, and that is part of our democratic form of Government.

Ms. ANDERSON. But we are getting too heavy with that sort of thing. You are killing the aging with this inflation, that is what is happening to them. You cannot buy a loaf of bread now, it is just terrible.

Senator CHILES. I just want to point out to you that some of our inflation is not entirely within our control, it would be nice if it was. One of the major causes of our inflation today is the fact that they are exporting $45 billion a year to buy energy.

Ms. ANDERSON. Yes.

Senator CHILES. Foreign oil.

Ms. ANDERSON. And you are bringing in everything else.

Senator CHILES. Well, that is $45 billion a year that is going out of our economy. Now, we have not found any kind of foreign oil that we can purchase to stop the Arabs from charging us that much for the oil, or the other people that have it, but of course that is why we have got to come up with a national energy program to try to start doing something about that.

Ms. ANDERSON. We all agree on that. You stand in line for 6 hours for a gallon of gas. I am really concerned about that. I wonder if Mr. Carter and all of you fellows up there are really that concerned.

Senator CHILES. Yes, ma'am. I can only speak for Lawton Chiles, you know. That is, I have more problems when I try to speak for everybody else, much less the President, but I think it is a major concern because it hits us in every area.

Ms. ANDERSON. Yes.

Senator CHILES. Inflation is costing us right now our military, and I just happen to be a person that does not believe that right now Russia is a benevolent power so that we do not need any kind of military strength. Right now, about 60 percent of our money for the military is going for salaries, and it is going for retirement, so that is leaving us very little. Then the other money that we try to spend for hardware or for weapons, the maintenance, that is higher than medical care.

Ms. ANDERSON. I won't go into the waste in military because I have seen some pretty bad incidents.

Senator CHILES. It hits us in all these areas.

Ms. ANDERSON. I just wanted to put in that plug. You keep on talking about a money need and here we are just inflating like crazy.

Senator CHILES. Yes, ma'am.

STATEMENT OF HELEN R. HEFFERMAN, TALLAHASSEE, FLA.

Ms. HEFFERMAN. I am a resident here at the building. I would like to pick up on a word that Mr. Carter and Dr. Reynolds mentioned, and that was prevention for different problems that the senior citizens have. I belong to a program that can answer that beautifully, and that is the foster grandparents at Sunland. At this time we only have 64, and the work that is being done is so advantageous to the senior citizens. They get up, dress nicely, and exchange ideas with each other. Besides that, we are taking care of the retarded children at Sunland, extending our love and care, and it is beautiful to see these children respond just to a touch from the foster grandparents. The only thing that I am interested in is, hopefully, that this program could be expanded. We have 64 foster grandparents and we need hundreds of them to cover this necessity.

Senator CHILES. I thank you for your testimony on that. We heard testimony yesterday and the day before about the benefits of that program, and I am sold on it. I hope we can have it expanded.

Ms. HEFFERMAN. We have plenty of applications but we have no money to pick up on them.

Thank you, sir.

Senator CHILES. Thank you, ma'am. I want to thank you all very much for your attendance, in being here today, and listening to our hearing, and other members of our audience as well. We will keep our record open for a few days so if you have these slips, or if you have statements you would like to make, we would be delighted to hear from you.

Miss Miller, we just want to thank you for providing these quarters for us and for the wonderful institution you have.

Miss MILLER. I really wanted the opportunity, on behalf of the residents and my staff, and our board of directors, to thank you very much for allowing us the privilege of having your hearing here. Thanks a million.

Senator CHILES. Yes, ma'am.

[Whereupon, at 11:34 a.m., the hearing adjourned.]

APPENDIXES

Appendix 1

MATERIAL SUBMITTED FOR THE RECORD

ITEM 1. LETTER AND ENCLOSURES FROM WILLIAM J. RISH,[1] FLORIDA STATE REPRESENTATIVE, TO SENATOR LAWTON CHILES, DATED JANUARY 27, 1978

DEAR SENATOR CHILES: You will recall that during the hearing which you held in Tallahassee for the Senate Committee on Aging, a question arose as to the ways in which Federal laws and regulations precluded Federal money in support of programs such as the home care for the elderly program which I sponsored during the last legislative session.

I am enclosing a memorandum to me from the Department of Health and Rehabilitative Services which describe how certain wording in title XX precludes Federal moneys for this type of family placement.

It was certainly good seeing you again and I surely appreciate all that you are trying to do to help not only the elderly of Florida but all the citizens of this State. If I can assist you in any other way in this matter, please don't hesitate to contact me.

Very truly yours,

WILLIAM J. RISH.

[Enclosures]

FLORIDA DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES,
Tallahassee, Fla., January 12, 1978.

Hon. WILLIAM J. RISH,
Representative, Tallahassee, Fla.

DEAR REPRESENTATIVE RISH: Following the discussion at the Senate Committee on Aging hearing held in Tallahassee prior to Thanksgiving, we have requested a response from the title XX unit within the department. The request was for any limitations on title XX for such activity as described in the Home Placement Act which you sponsored. The reply is attached for your use.

If I can be of further assistance, please let me know.

Sincerely,

E. BENTLEY LIPSCOMB,
Program Staff Director,
Aging and Adult Services.

[Attachment]

JANUARY 6, 1978.

Subject: Information on Title XX Funding Limitation for Family Placement
To: PDAA (E. Bentley Lipscomb)

(1) Pursuant to your December 30 request for a qualitative statement on the title XX funding limitation for family placement, the following information is provided:

In accordance with the HEW regulations 45 CFR 228.40 and 228.41, title XX funding may not be used for room and board and medical care unless they are provided as integral but subordinate to a discrete social service. "FFP is not available for medical and remedial care, other than family planning services, except when they are an integral but subordinate part of a service described in the services plan, and the medical and remedial care is not available to the

[1] See statement, —.

individual under the State's approved title XIX plan and to the extent the individual or the provider is not eligible to receive payment under title XVIII for the provision of the service to the individual." 45 CFR 228.40(a) "FFP is not available for room or board under a services plan, except when provided in emergency shelter under 228.46, or as an integral but subordinate part of another service and then only for a period of not more than 6 consecutive months for any one placement. Room or board is deemed to be as an integral but subordinate component of a service if: (1) It is necessary to achieve the objective of that service and not merely to provide food and shelter; and (2) room or board are included in the State's services plan along with the description of the service of which it is an integral but subordinate part, and is provided in accordance with all applicable requirements under this part." 45 CFR 228.41 (a) (b).

As federally mandated, the medical care and room and board must be necessary to achieve the objective of the discrete service and specific descriptions of their integral and subordinate nature must be delineated in the comprehensive annual services program plan (CASPP). Since the family placement service has room and board as a primary component rather than being subordinate to a discrete social service, family placement is not described as a title XX funded service in the CASPP.

(2) The title XX regulations with the pertinent sections marked are attached for your information. If you have any further questions, please do not hesitate to contact this office.

FRANCES KOLDEWEY,
Director, Office of Health and Social Services Policy Development.

ITEM 2. LETTER AND ENCLOSURE FROM GEORGE H. SHELDON, FLORIDA STATE REPRESENTATIVE, TO SENATOR LAWTON CHILES, DATED JANUARY 4, 1978

DEAR LAWTON: Please accept my apologies for the confusion over the timing of your recent hearing in Tallahassee. I wanted very much to attend. Nevertheless, there were several points that I wished to make about the issue of "alternatives" to institutionalization of the elderly. Perhaps this letter will serve in lieu of my testimony before the committee.

To begin with, effective alternatives already exist. In our own State, the Dowling Park program of Mr. J. Pomeroy Carter and the Miami Jewish Home and Hospital for the Aged administered by Mr. Fred Hirt present outstanding examples of what an innovative application of resources can accomplish for the elderly. Programmatically, these two facilities offer superb alternatives by presenting elderly persons with a choice between total independence and total institutionalization. For some people a nursing home or other institution is the only suitable option, but others, now in such facilities, the opportunity for partial, independent living would be a desirable and humane alternative.

If the Federal Government desires to promote such innovative alternatives, consideration must be given to restructuring the financing of the medicare, medicaid, and supplemental security income programs.

Present financing systems are actuated upon the demonstration of a need for medical care which perpetuate treatment-focused rather than environmentally-focused programs. Campus or village-type programs for the elderly presume at least partial independent living capability. This means that the person who participates in these programs would live independently most of the time while having medical treatment available when needed.

In summary, when your committee develops policy on this issue, it should give attention to how the financing of programs for the elderly might be used to encourage the establishment of alternatives to institutionalization of the campus or village type which provide more than simple medical care.

I am enclosing for your study a copy of our report of the Ad Hoc Subcommittee on Nursing Homes. This report deals primarily with nursing home problems but does give some attention to the question of how to promote alternatives for the elderly.

Sincerely,

GEORGE H. SHELDON.

[Enclosure]

REPORT OF THE AD HOC SUBCOMMITTEE ON NURSING HOMES*

INTRODUCTION

The Ad Hoc Subcommittee on Nursing Homes was established to (1) examine the structural, regulatory, and financial characteristics of the nursing home system in Florida, (2) make recommendations for changes in policy which would improve the performance of that system, and (3) explore what alternatives to nursing home care are or could be made available.[1] Interest in the creation of this subcommittee was generated as a result of:

—Disclosures at both State and Federal levels of inadequate and, in some instances, abusive treatment of nursing home residents;[2 3]
—the increasing number of bills brought before the legislature which would alter present statutes affecting nursing homes;[4]
—frequent constituent complaints received by legislators about nursing home care; and
—the yearly requests by the nursing home industry for increases in appropriations for nursing home services under the Florida Medicaid Program.[5]

ORGANIZATION OF MEETINGS

The subcommittee initially determined that the subject of nursing home care was of sufficient public concern to warrant monthly meetings and hearings throughout the State. These meetings took place between September and December of 1975.[6] In each area of the State, the subcommittee structured its meetings so that prepared testimony from industry, agency, and organized consumer representatives might be presented according to an established agenda.[7] Upon completion of this agenda, public hearings were held.[8] In addition, written and supplemental testimony was received by the subcommittee from numerous individuals and groups. In this manner it was possible to acquire a broad perspective of nursing home services and problems. This report attempts to briefly consolidate the findings of these meetings and to make recommendations which respond to some of the major issues and concerns raised.

APPROPRIATIONS CONSEQUENCES

At the outset the reader should be mindful of the economic context within which this report is written and recommendations made.[9] What is included is felt

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*Submitted to the Committee on Health and Rehabilitative Services of the Florida House of Representatives. Approved by the subcommittee Jan. 13, 1976.

[1] Letter of June 27, 1975, from Representative Barry Kutun, Chairman of the House Health and Rehabilitative Services Committee, to Representative George Sheldon appointing him Chairman of the Ad Hoc Subcommittee on Nursing Homes and providing the subcommittee with its charge.

[2] Introductory report of the Subcommittee on Long-Term Care of the Special Committee on Aging, U.S. Senate, November 1974 (Moss Report).

[3] Pat Allen, "Nursing Homes: Haven or Hell?" *State Government News*, October 1975, pp. 2–6. This article indicates the existence of State-level investigations of nursing homes underway during 1975 in Massachusetts, New York, New Jersey, Nevada, Connecticut, Minnesota, Michigan, Rhode Island, North Dakota, Wisconsin, and Illinois.

[4] During the 1975 Session of the Legislature 22 bills were introduced in the House and Senate which affected nursing homes; of this number six were companion bills. The bills introduced were House Bills 373, 492, 796, 1208, 1361, 1363, 1705, and 1739 and Senate Bills 31, 173, 235, 287, 556, 567, 541, 1034, 1099, 1202, and 1238. Enacted into law were HB 1361 and SB 31, 567, and 777 to which HB 1363 and SB 1238 were attached.

[5] In fiscal year 1970–71 when the medical program was first initiated, the legislature appropriated $24,931,922 for nursing home care (Chapter 70–95, *Laws of Florida*). By fiscal year 1975–76 this figure had risen to $68,386,386 (Chapter 75–280, *Laws of Florida*), an increase of 274 percent over 6 years.

[6] Hearings were held in the following areas: Tampa—Sept. 19, St. Petersburg—Sept. 20, Daytona Beach—Oct. 17, Panama City—Nov. 14 and 15, Hollywood—Dec. 12, and Hialeah—Dec. 13.

[7] Agenda are included in appendix A.

[8] During the meetings testimony was provided to the subcommittee by individuals and organizations listed in appendix B.

[9] As of this writing a $42.5 million general revenue shortfall for fiscal year 1975–76 has been projected. In addition, predictions have been made of cost overruns in the medicaid program of $24 million. On Dec. 22, 1975, Secretary William J. Page, Jr., of the Department of Health and Rehabilitative Services (DHRS) recommended tightening of eligibility criteria and cutbacks in payment schedules for certain services. Among those services cut back was nursing home care in which the cap for payment of such services was reduced from $600 to $585 per month for skilled nursing home care.

by the subcommittee to constitute a minimal program of reform which should not be viewed as an ideal toward which the legislature might work over a period of years. This is not to suggest that the subcommittee believes its recommendations to be wholly without appropriations consequences, but rather that as the legislature undertakes to establish its priorities this year, it should be aware of the subcommittee's responsible effort to contain the cost of its suggested program.

OBJECTIVES

The report that follows will be structured to specifically respond to the subcommittee's charge.[10] The four areas of chief concern in this charge were to determine:

(1) The extent to which nursing home licensing laws and regulations impact on the quality and cost of care provided by nursing homes.

(2) Whether rates established are equitable in relation to the cost of nursing home care.

(3) The most appropriate criteria for measuring and insuring quality care for patients in nursing homes.

(4) The potential of alternative methods of care of nursing home patients and their effect on nursing home costs, utilization rates, and care.

These major areas of concern are organized into subcategories as appropriate.

GENERAL FINDINGS AND RECOMMENDATIONS

The subcommittee upon examination of the available evidence and testimony concludes that despite a heavy Federal and State commitment to long-term care, a coherent and consistent policy on what quality and type of health care should be provided in nursing homes has not been developed. In part the absence of such a policy may be attributed to a more general inability of public policy makers at all levels to arrive at a consensus on what character the Nation's health delivery system should assume. Nevertheless, this does not account for the apparent fact that nursing homes have usually been regarded as an adjunct to but not a component of the health care system in the United States. One reason for this "outsider" role is that the long-term care provided in nursing homes is foreign to the acute-care model under which most of today's health professionals practice.

Another reason is that there is a negative attitude toward nursing homes which pervades the professional health community and to some extent society as a whole.[11] [12] [13] This feeling is a consequence of several factors: the abuse of patients in nursing homes which has been frequently reported in the media, the unfortunate psychological association of nursing homes with inevitable death, the guilt sometimes felt by relatives who place their loved ones in nursing homes, the very real instances of insufferable and occasionally illegal conditions which have been permitted or tolerated in some nursing homes by health care practitioners and health facility inspectors, and the belief among certain parties that the proprietary sector[14] has no place in the health delivery system since the profit motive provides an incentive to compromise the quality of care delivered in the interest of higher earnings.[15]

This negative attitude, while to some extent justified by factual evidence, has worked to the disadvantage of nursing home residents and served as an obstacle to meaningful reform. The nursing home industry is by no means without its shortcomings; but at this point it is meeting a very real social need not likely to be met by another system at the present time. Given the continuing existence

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[10] Letter from Representative Kutun to Representative Sheldon cited in footnote 1.

[11] Testimony before the subcommittee of Dr. Vernon Astler, president of the Florida Medical Association, on Nov. 14, 1975. (See Physicians Service section on page 24.)

[12] Correspondence to subcommittee staff from Joyce L. Niece, R.N., dated Dec. 10, 1975, stated that, "An individual in charge of a nursing program in this State tells the student that there are two places an R.N. should never work—in a nursing home and in the operating room—because it is a waste of their professional ability."

[13] U.S. Senate, Subcommittee on Long-Term Care of the Special Committee on Aging, Supporting Paper No. 3, "Nursing Home Care in the United States: Failure in Public Policy (Doctors in Nursing Homes: The Shunned Responsibility)," February 1975.

[14] In testimony before the Subcommittee on Sept. 19, 1975, Dr. Charlton Prather indicated that 75 percent of Florida's nursing homes are private, for-profit facilities.

[15] According to Val Halamandaris, Associate Counsel for the U.S. Senate Special Committee on Aging, the most sensitive indicator of good care in nursing homes is the ratio of registered nurses to patients. Whether nonprofit or public nursing homes provide better care than proprietary homes has not been demonstrated at this time. (Personal conversation between subcommittee staff and Mr. Halamandaris on Nov. 10, 1975.)

of these facilities, the critical issue becomes: "What sort of place should a nursing home be?" Once this matter is decided, the State may then go about establishing standards to insure that only such homes are in operation.

REGULATION

The ultimate objective of regulation of nursing homes is to insure that minimum standards of patient care are present in a given nursing home before a facility is given a license to operate in a State.[16] Such regulation should, in effect, operationalize policy objectives in this area. However, there is evidence to indicate that only a small fraction of the regulations now in effect provide the capability to directly assess the quality of patient care in nursing homes.[17] [18] Moreover, the very complexity and frequency of the regulatory process consumes considerable professional staff time.[19] The subcommittee has therefore determined that, although genuinely motivated by the public interest, the regulatory process has evolved into a sometimes counter-productive system out of step with society's aims for nursing homes. The subcommittee found that the nursing home regulation program:

—Was inappropriately launched on the basis of a hospital model which is oriented toward acute rather than long-term care. In acute care hospitals the physician plays a more central role in the delivery and monitoring of services to patients than in a long-term care facility. With this close patient/physician relationship attending to patient needs, it is appropriate for hospital regulation to concern itself primarily with physical structures and hardware. In contrast, physician visits in long-term care facilities are infrequent in most cases which suggests a need for greater emphasis upon regulation which monitors patient care.[20] [21]

—Has evolved in an uncoordinated fashion at the Federal level which results in regulations being scattered over various issues of the *Code of Federal Regulations* and the Federal Register. State regulations in Chapter 10D–29 of the Rules and Regulations of the State of Florida afford a more logical system for application of the nursing home licensure law; however, these State regulations must be in essential agreement with the Federal code which is constantly changing. This leads to a perpetual disequilibrium of policy between State and Federal rules which at times contributes to confusion among State licensure personnel, medicaid staff, providers, and patients.

—Consistently fails to account for the potential economic impact of regulations. Under existing rulemaking procedures at the Federal level, pressure to increase costs of care is constantly present. This is not to suggest that all rules are patently inappropriate owing to increased costs, but instead

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[16] Licensure constitutes permission to operate a certain facility and/or provide a certain service in a State. It is mandatory. Certification is a voluntary program in which a facility agrees to meet certain standards in order to be certified as eligible to provide services to a given class of buyers. Medicare and medicaid are certification-based programs.

[17] Moreland Act Commission, Regulating Nursing Home Care. The Paper Tigers, October 1975, pp. 31-43. This recent report included an analysis of Federal regulations and reporting forms which found that only 30 out of a total of 575 items on reporting forms actually required patient observation. Moreover, this study also conducted a comparative analysis of survey results and period medical review findings. This analysis applied a Pearson correlation coefficient test and found "no statistically significant correlation between any PMR index and any survey index." This finding demonstrates the lack of association between quality of medical care delivered in a nursing home and the results of inspection surveys.

[18] Department of Health, Education, and Welfare (DHEW), Long-Term Care Facility Improvement Study (introductory report), July 1975, pp. 14–15. This study concluded that: "Present survey items reflect the regulations which, in turn, are based on a hospital model and should be redesigned to assess patient care in long-term care facilities . . . [This study] document[s] that paper compliance alone provides insufficient evidence to show that quality care is being provided to patients in a safe environment."

[19] Testimony of the Florida Association of Homes for the Aged presented before the subcommittee on Sept. 19, 1975, contended that: "At the present, from 3 to 4 hours of the registered nurse's workday is spent in documentation which takes her away from delivering quality nursing care."

[20] Op. cit., Long-Term Care Facility Improvement Study, p. 12.

[21] In a conversation between subcommittee staff and Jim Ammons of the region IV office of nursing home affairs of the Department of Health, Education, and Welfare (DHEW), it was learned that at the present time Federal officials are reexamning regulations affecting long-term care facilities for the purpose of implementing a patient outcome approach and moving away from a facilities-based system. Mr. Ammons also observed that while Florida certification studies were usually submitted in a timely fashion, their orientation was clearly toward facilities rather than performance in terms of patient care.

that benefits which accrue from regulation must be calculated so that they are not exceeded by costs. In our haste to improve conditions, reason must be exercised so that costs are not increased to the point where fewer persons are able to receive nursing home care because of its high cost.[22]

—Is presently carried out by independent representatives of three distinct units with the DHRS (i.e., Health Program Office, Social and Economic Services Program Office, and Office of Administrative Services).[23] This fragmentation has resulted in a proliferation of inspections and required documentation. To some extent this fragmentation contributes to a system of checks on performance; however, it is questionable whether the advantages of such checks outweigh the disadvantages of excessive paperwork and time occupied in documentation. (See appendix C.)

—Is largely a matter of business between the DHRS personnel and nursing home administrators. The valuable information which is generated through inspection surveys is not easily accessible to the public. This information could prove to be of significant value to potential residents and their relatives when attempting to locate a nursing home.

—Provides little guidance to inspectors or administrators respecting those deficiencies which are the most and the least serious from the standpoint of life and safety or level of patient care. Substantial discretion remains with the DHRS respecting what action, if any, should be taken in the event of deficiencies. Such discretion has led to a lack of uniformity in application of licensure and certification regulations.

—Does not provide for an ongoing analysis of inspection results. All inspection surveys are now filed individually without being subject to comparison with other surveys on a regional basis or on the basis of any of a number of other appropriate parameters. This data, if available in an easily retrievable form, could provide a foundation for evaluating at any point the performance of any individual nursing home or group of nursing homes as well as suggest areas which indicate a need for increased enforcement.

—Does not have members representing the public on the board of examiners of nursing home administrators.

Beyond compulsory systems of regulations, the nursing home industry has the option to adopt a program of voluntary accreditation such as that in use for hospitals under the joint commission on accreditation of hospitals. An accreditation program essentially provides a means for voluntary compliance with a specified program of nationally adopted standards. The value of such a program lies largely in the opportunities it offers facilities to upgrade and improve their management and service delivery capabilities while making a public commitment to provide a high quality of care. To date, the nursing home industry has chosen not to pursue this method of self-regulation since additional costs are thereby involved and another mechanism—albeit voluntary—of inspection would be in place. Although the subcommittee recognizes that initial costs would undoubtedly be incurred upon establishment of an accreditation system, it is also likely that improved management skills might offset such added costs and improve patient care.

To a degree, a philosophy of self-regulation has been adopted by the Florida Nursing Home Association through its peer review program. This program establishes a State peer review committee to investigate complaints against member homes and nonmember homes which consent to investigation by the association. The effectiveness of this program has yet to be demonstrated since it has only recently been implemented, but this approach should be encouraged if it contributes to a substantive improvement in patient care.

As a result of action by the 1975 legislature, the DHRS is presently undergoing a reorganization which has the potential for significantly improving the process of nursing home regulation.[24] Under this reorganization the licensure and certification programs of the DHRS are expected to be decentralized to the district level. This decentralization should improve coordination of inspection at

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[22] Murray L. Weidenbaum, "Where Overregulation Can Lead," Nation's Business, June 1975, p. 32.

[23] The reorganization of the DHRS (See Chapter 75–48, Laws of Florida) at the time of this writing had not proceeded to the point of fixing structural responsibility for licensure and certification of health facilities. Secretary William J. Page, Jr., stated in his remarks before the subcommittee on Dec. 12, 1975, that: "It is my expectation that by decentralizing the licensure/certification operation to the districts [of HRS] on or before July 1, 1976, improvements in this key program will continue, if not actually accelerate."

[24] See chapter 75–48, Laws of Florida.

the local level and may bring the process closer to the consumer, but it may at the same time lead to a closer relationship between inspectors and the industry which could threaten the objectivity of inspectors. The DHRS program offices responsible for monitoring the performance of inspectors should be mindful of this possibility and act to insure uniformity of application and enforcement of regulations.

The subcommittee, upon review of the above findings, recommends that the regulatory element of the State nursing home program be altered as follows:

1. A single unit at the State level should be created within the DHRS to coordinate the district licensure and certification program.

2. Where possible, inspections now conducted by county health units should be incorporated under the general duties of the district licensure and certification teams.

3. The position of director of social work services in the office of licensure and certification which has been available to the DHRS since May of 1975 should be filled. This position is 100 percent federally funded and was established specifically for the purpose of reorienting the essentially hardware-based licensure system toward a concept of patient care outcome.

4. Minimum qualifications for inspection teams should be reassessed. Inspectors should be able to evaluate the general condition of patients, not merely facility hardware. Moreover, regular programs of continuing education should be established for surveyors in order to improve their skills, promote uniformity in the interpretation of regulations, and keep surveyors up to date on changes in policy and regulations.

5. Voluntary self-inspection should be a part of every facility's internal management program. This may be accomplished if the DHRS provides every facility with copies of Federal and State survey forms, regulations, and interpretive guidelines. Facility administrators would then be able to distribute parts of regulations to appropriate departments in each nursing home so that these departments can evaluate their own performance. If this were done, facilities would realize, prior to actual surveys, what is expected, what regulations are unclear, and what weaknesses exist.

6. After consultation with industry, professional, and consumer groups, the DHRS should amend all nursing home licensure regulations so that the text of each appropriate regulation or subpart thereof reflects by uniform code the extent to which noncompliance with such regulation constitutes a threat to the health and safety of residents. Three coded levels of severity of violation are recommended: (1) Class "A" violations are violations which the DHRS determines to present an imminent danger to the residents or guests of a nursing home or a substantial probability that death or serious physical harm would result therefrom. (2) Class "B" violations are violations which the DHRS determines to have a direct or immediate relationship to the health, safety, or security of long-term care patients, other than Class "A" violations. (3) Class "C" violations are violations which the DHRS determines to have an indirect or long-range relationship to the health, safety, or security of long-term care patients, other than Class "A" or "B" violations. Citations should specify the time within which the violation is required to be corrected.

If the violation is corrected within the time specified, no civil penalty (fine) should be imposed. If uncorrected within the time specified, fines as specified by law should be imposed and each day thereafter should constitute a separate violation. If not corrected within a reasonable period of time, a facility should be closed.

7. The DHRS should promulgate and publish uniform criteria for the evaluation of nursing homes with respect to their compliance with the standards, as indicated by the results of the inspections conducted. Such criteria should include a detailed listing of the types and degree of severity or unacceptability of deficiencies which inspections might indicate and in which nursing homes notably and significantly exceed required minimum standards. In promulgating such criteria, the DHRS should devise a system of rating nursing homes in accordance with the deficiencies and areas of significantly high care and performance which the reports of inspection have indicated. Such system should include no less than five specific rating categories. The rating assigned to each nursing home on the basis of its immediately prior inspection should be deemed a part of the results and findings of that inspection and should be required by the DHRS to be posted conspicuously within and outside of the facility to which it applies and in all advertising or published materials. Ratings assigned should be forwarded to the appropriate district nursing home ombudsman committee

for review and comment. A facility should be able to appeal the assignment of a particular rating to the DHRS within a reasonable period after notice of its assignment.

8. When new Federal and State regulations are issued, providers and surveyors should be briefed at the same session on interpretation of regulations. In this fashion both inspectors and providers will have a similar understanding of new requirements.

9. By law, a schedule of unannounced inspections should be required with a provision for penalties for any employee who divulges such schedule to any unauthorized person.[25]

10. A file of complaints received by the DHRS regarding nursing home care and subsequent investigation reports should be maintained independent of general licensure files for purposes of analysis and monitoring of frequency and type of complaint and resultant findings.

11. Computerized systems should be employed for purposes of collection and retrieval of data related to nursing home inspections. Such systems would permit an instant and/or ongoing analysis of the general performance of a single nursing home or group of homes and would serve as an invaluable tool for monitoring the performance of inspectors on a district and statewide basis.

12. The Department of Health, Education, and Welfare (DHEW) should promptly proceed with a comprehensive revision of existing regulations in order that they may be better coordinated, more succinct, cost-beneficial, patient-focused, and require less documentation.[26]

13. When a nursing home is closed, a receiver should be appointed by the State to effect the transfer of residents to other homes and to protect the rights of the residents and the State.

14. A statement of legislative intent should be included under section 400.23 of the nursing home licensure law to provide for a regulatory emphasis upon patient care.

PHARMACEUTICAL SERVICES

The use of pharmaceuticals in the rehabilitative program of long-term care residents is a necessary ingredient of most medical treatment plans. However, when such pharmaceuticals are controlled substances, they should be dispensed and managed with considerable care. Nursing homes are heavily regulated in this area; however, problems of control continue to exist. In addition, financial and medical problems appear to be common in connection with the use of drugs.

The subcommittee found that with respect to pharmaceutical services:

—Florida may be having an experience similar to the rest of the Nation with respect to the existence of kickbacks between pharmaceutical providers and nursing homes.[27] This information first came to light as a result of the activities of the DHRS' Nursing Home Pharmaceutical Study Committee.[28]

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[25] Unannounced inspections are now required under a recent change in Federal and State policy.

[26] U.S. Representative Claude Pepper of Miami has agreed to assist the subcommittee in transmitting its findings to DHEW.

[27] Testimony of Mr. Jack Jones, chairman, nursing home pharmaceutical study committee, and pharmaceutical consultant to the DHRS, on Sept. 19, 1975.

[28] Although esentially complete in its draft form, the DHRS has not to date taken action to approve the report of the nursing home pharmaceutical study committee. This draft defines kickbacks, rebates, and discounts as follows:

"Discount—A reduction in the gross cost of goods or services provided legitimately earned based on usual and customary factors of business such as early payment, volume purchases, reciprocal services rendered by the nursing home, or the nursing home assuming the risk for bad debts. Discounts are not excessive in percentage amount and are reflected in the financial records of the pharmacist and the nursing home. In the long run, discounts should be partially or wholly passed on to the resident of the nursing home who purchase drugs from the provider pharmacist.

Rebate—Where a nursing home takes back a dollar percentage of all drugs delivered. A rebate is not based, as a discount is, on any reciprocal service by the nursing home. A rebate is in the form of money only and is not necessarily reflected on the books of the pharmacy or nursing home.

Kickback—A kickback is similar to a rebate except that it is more under the table and is not always in the form of money. Kickbacks are given both to get business in the first place and subsequently to keep the account. Kickbacks may take the form of money, durable goods such as cars or television sets, vacations, renting space in the nursing home at exorbitant amounts, paying all or part of the salaries or wages of nursing home staff who provide little or no actual assistance to the pharmacist, buying advertising space in the nursing home newsletter or promotional literature at inflated rates of excessive amounts of space at regular rates, or purchasing stock in the nursing home corporation. Kickbacks as described by the U.S. Senate Committee are forced on the provider as a condition of doing business.

To summarize on the above definitions, discounts, where they are earned and reasonable, are ethical and are, in fact, encouraged in order to pass on savings to the consumer (as additional costs are passed on); excessive discounts, rebates, and kickbacks are unearned and unjustifiable and are considered unethical business practices."

The preliminary findings of this departmental committee indicate that arrangements for kickbacks, rebates and discounts exist within the State although the scope of such arrangements is unknown. When such kickbacks, rebates, and discounts exist, they impede normal market forces and tend to increase prices to the purchaser. In the case of nursing home patients, the purchaser is usually an individual on medicaid which means unnecessarily high costs to the State.

—The $20 cap on payments for prescribed medication may be unduly restrictive in that nursing home patients represent a unique class with a greater need for pharmaceuticals than most recipients of prescribed medication under the medicaid program. When costs for medication exceed the $20 cap, they are sometimes borne by the nursing home.

—The contract between the DHRS and the paid prescriptions[29] has been characterized by controversy with respect to (a) delays in reimbursement to providers of pharmaceuticals; (b) the manner in which decisions are made about who is and is not to be eligible for a waiver of the $20 cap on prescribed medication;[30] and (c) the reinstatement of the $20 cap after paid originally agreed to provide prescribed medication without such a limitation.

—The patient and practitioner profiles generated by the paid program have provided useful tools for analysis and evaluation of patient needs and patterns of medical practice demonstrated by practitioners.[31]

—The residents of nursing home facilities are frequently over-medicated and more often than not such excess medications are central nervous system drugs, pain killers, tranquilizers, or sedatives.[32] [33]

—In Federal regulation, nursing homes are required to have on their staffs a consulting pharmacist whose function it is to evaluate the drug management program of the facility and the quality and type of drugs delivered. In many instances the consultant pharmacist retained by a nursing home is also its chief provider of pharmaceuticals. This arrangement, although frugal, can result in a conflict of interest since the pharmacist who manages the drugs of a nursing home is in fact monitoring his own work.

Upon review of these findings the subcommittee recommends that:

15. The DHRS should report to the legislature respecting the financial and policy development implications of establishing a system providing a higher cap for prescribed medication in nursing homes. The concept of a cap appears worth retaining in view of the patterns of over-medication demonstrated by physicians however, $20 appears at this time to be an unreasonably low figure.

16. The DHRS should closely examine the paid precsriptions contract in order to determine the performance of this third-party provider. While it is recognized that much valuable information is produced by this system, it must also be acknowledged that in many respects the conditions under which this contract was let have not been met by paid.

17. The DHRS should consider the cost-benefit potential of innovative systems of drug management now available to nursing homes. The "unit dose" system and other such regimens may be of significant value in terms of proper dispensation of pharmaceuticals and recovery of unused or terminated drugs.

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[29] Paid prescriptions is a private, nonprofit corporation presently under contract with the DHRS to manage the entire prescribed medication component of the Florida medicaid program.

[30] Testimony presented by Mr. David Hodge, executive director for Paid prescriptions in Florida, sets forth criteria used by his organization to establish whether an individual on medicaid is eligible for drug allotments in excess of $20. "The main criteria," he stated, "are that the drugs must be medically necessary and indicated according to the justification or the diagnosis provided for that drug." Whether a drug is medically necessary is a medical judgment made by physicians serving as consultants to the paid program.

[31] This finding was corroborated by supporting paper No. 2, Drugs in Nursing Homes: Misuse, High Costs, and Kickbacks, by the Subcommittee on Long-Term Care of the Special Committee on Aging of the U.S. Senate (p. X) which found that: "Almost 40 percent of the drugs in nursing homes are central nervous system drugs, painkillers, sedatives, or tranquilizers." In addition, the office of nursing home affairs of the DHEW is undertaking an in-depth analysis of drugs ordered for nursing home patients which will be reported in the near future.

[32] Testimony submitted to the DHRS medicaid task force by Mr. Jack Jones entitled: "Concerns of Florida Pharmacists Pertaining to the Florida Medicaid Program."

[33] These profiles are employed to inform physicians of how they might improve their method of prescribing medications and have, according to paid, been well received by the medical community. (Testimony before the subcommittee by Mr. David Hodge on Nov. 14, 1975.)

18. Public Law 92–603 prohibits kickbacks between nursing homes and pharmacists; however, regulations long overdue have never been promulgated by the DHEW. This would indicate a need for State action at the legislative level in order to curb these practices.

19. Physicians should be urged to use greater discretion when formulating drug programs for nursing home patients. Professional associations should work to educate their members about the hazards and rehabilitative consequences of over medication.[34]

STAFF TRAINING

Despite the ever-increasing proportion of elderly persons residing in Florida, there appears to be no substantial or coordinated effort to develop specialized geriatric training for those professions which must assist in meeting the health-related needs of these major population group.[35] With respect to this problem, the subcommittee learned that:

—Federal regulations include no specific guidelines for staffing of nursing homes with licensed nurses. Florida, through its licensure regulations, requires at least one registered nurse to be on the floor during the A.M. shift 7 days a week and one R.N. to serve as supervisory director of nursing 5 days a week.[36]

—Neither Federal nor State laws or regulations stipulate that personnel providing services to the long-term care resident must have training in geriatric care.

—At present there is no program within the State postsecondary educational system which provides training for nurses or physicians wishing to pursue a specialty in geriatrics.[37] Perhaps more critical is the almost total absence of qualified personnel to teach in the field of geriatric nursing and other related fields.

—Despite a pressing need for better qualified nursing home administrators, there is no specialized educational program in Florida which prepares individuals for this field.

—State and Federal regulations place no training requirements upon patient care staff below the level of licensed nurse.[38] More often than not, it is these aides and others ancillary personnel in the lowest pay grades that are in most frequent contact with the resident of long-term care facilities, a situation which increases the likelihood for patient maltreatment, neglect, or abuse.[39]

—Nurses commonly regard work in nursing homes as too demanding, unsavory, lacking in intellectual challenges, and under-paid.

The subcommittee recognizes that whatever additional requirements are placed upon a nursing home to upgrade the training requirements of staff will result in increased costs. However, it is also recognized that such training constitutes the single most critical factor which could contribute to improved patient care and the enhancement of the overall living environment of nursing homes. With this in mind, the subcommittee recommends:

20. Appropriate degree-related and continuing inservice support programs in geriatric medicine and nursing be developed and offered in the state post-secondary educational system. Where degree-related, an internship in a long-term care facility should be required.

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[34] As of Dec. 2, 1975, each nursing home is required to employ a medical director to assume: "Responsibility for the overall coordination of the medical care in the facility to insure the adequacy and appropriateness of the medical services provided to patients and to maintain surveillance of the health status of employees." (Excerpted from draft guidelines implementing Code of Federal Regulations, chapter 45, part 405.1122.)

[35] Senator Robert Graham recently stated: "Only a few years ago, we had one elderly person for every six working persons. Today the ratio is 1 to 3 and in 25 years it will be 1 to 1." Miami Herald, Dec. 14, 1975. Senator Graham was referring to information published by the University of Florida's Bureau of Economic and Business Research.

[36] See Rules and Regulations of the State of Florida, chapter 10D–29.09.

[37] With the help of Federal funds, the University of Miami (a private institution) has established a program to train gerontological nurse practitioners. This program presently is training 25 post-baccalaureate students.

[38] See Rules and Regulations of the State of Florida, chapter 10D-29.18.

[39] The U.S. Senate Subcommittee on Long-Term Care, in its supporting paper No. 4 entitled Nurses in Nursing Homes: The Heavy Burden (The Reliance on Untrained and Unlicensed Personnel), cites the example of a Texas investigation which found that: "Fifty percent of the complaints against nursing homes . . . were caused by unlicensed, uncontrolled health care workers." (p. 373) Among those complaints noted in this study were (1) drinking on the job, (2) sleeping on duty, (3) abusing patients, (4) stealing patients' belongings, (5) showering patients in hot or cold water as punishment, (6) eating patients' food, and (7) stealing medications.

21. The number of qualified faculty members with preparation in the fields of gerontology and geriatric nursing be increased by providing graduate programs in these fields at the Master's level.

22. Inservice programs for geriatric aides be expanded to a sufficient number of community colleges to serve the entire state.[40]

23. Nursing homes should establish improved and expanded systems of career development of personnel in the lower pay ranges to provide an incentive for the enhancement of the skills of aides and orderlies and to reduce staff turnover at this level.

24. Nursing home administration as a distinct program should be offered at both the associate and baccalaureate levels in at least one major State post-secondary educational institution.

25. Vocational-technical programs at the high school level should provide training for geriatric aides and orderlies on a regular curriculum or inservice basis.

26. The DHRS should establish minimum qualifications for aides and orderlies in nursing homes.

PHYSICIAN SERVICES

Because of the particular organization of the health care system in the United States, ultimate responsibility for establishing and monitoring standards of health care and treatment rests with the physician. Government has traditionally assumed the regulatory role of enforcing minimum standards for institutions in which health services are delivered but has generally left decisions respecting the appropriateness of medical treatment to the health care practitioner.

In the case of acute-care institutions (e.g., hospitals), practitioners have played a significant role in assessing the quality and type of treatment delivered to patients because of the frequency with which they visit these facilities. In contrast, under normal circumstances the long-term care resident is rarely visited by a practitioner, and evidence indicates that in many instances physicians fail to see their patients in these facilities as often as required by regulation.[41] [42] Owing to the uniqueness of their schedule of treatment, long-term care facilities are typically not subject to the same degree of quality-of-care monitoring by physicians as are acute-care facilities.

A recent development, prompted by a change in Federal regulations, is expected to improve the degree to which physicians are involved with long-term care facilities. It is now required that every skilled nursing facility retain a medical director who is responsible for the coordination of medical care.[43] This regulation, where properly observed, should significantly enhance the quality of care in nursing homes by establishing a program of regular physician surveillance.[44]

In the area of physician services, the subcommittee found that:

—"Doctors really don't want to go to nursing homes because the results are not dramatic, the people's baseline is rather stable, in other words they are

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[40] In a letter dated Dec. 18, 1975, Mr. John M. Schmieder, director, Allied Health Division of Palm Beach Junior College, indicated that his program has recently completed a geriatric aide inservice curriculum under department of education grant No. 750–150. Such curricula should be made available statewide.

[41] Dr. Charlton Prather, director of the health program office of the DHRS, stated in testimony before the subcommittee on Sept. 19, 1975, that the most frequent violation of nursing home certification regulations is the absence of the specified number of physician visits to a resident in spite of the fact that such visits are required on a relatively infrequent basis. According to section 405.1123 of the Code of Federal Regulations, chapter 45, the physician must visit medicare and medicaid patients at least once every 30 days for the first 90 days of residence in a skilled nursing home and at least once every 60 days thereafter.

[42] The Dec. 8, 1975, issue of American Medical News (a publication of the American Medical Association stated that: "A requirement that a physician visit his patient in a skilled nursing facility at least monthly for the first 3 months of confinement and at least one every 2 months after that is not unreasonable, reported the AMA council on medical services. The House of Delegates concurred. The council noted that the level of care provided in a skilled nursing facility is of a high enough level to justify the physician-visit requirement now contained in Federal medicare and medicaid regulations.

[43] See footnote 34.

[44] In correspondence dated Dec. 29, 1975, between Representative Sheldon and Dr. Vernon Astler, president of the Florida Medical Association, Dr. Astler observed that: "The employment of a full- or part-time medical director for nursing homes will aid greatly in coordinating health services between the practicing physician and the nursing homes." Dr. Astler further noted that: "The medical director, pharmacist and nurse, working together, will eliminate a number of problems in [the area of overutilization of drugs in nursing homes]."

not getting seriously worse in a rapid way nor are they getting . . . better in a rapid way, and the doctors don't see results." [45]

—Medical findiugs and physicians' orders are frequently not properly documented in nursing homes.[46]

—Patients are occasionally admitted to nursing homes on the recommendation of an emergency room physician, leaving the patient with no attending physician for purposes of ongoing treatment.

—A better awareness of the problems of nursing homes and their residents appears to be developing among physicians as well as recognition of the fact that physicians must play a key role in improving conditions.[47]

In consideration of these findings, the subcommittee recommends:

27. The medical director now required in skilled nursing facilities, in cooperation with local medical and osteopathic societies, should develop systems for admission, monitoring, and continuity of treatment in his or her facility.

28. The professional associations of medical doctors, osteopaths, and nurses should encourage their local chapters and societies to establish active standing committees on long-term care to improve conditions, management, and relationships with nursing homes. Such committees should include members of the nursing home provider, resident, and elderly advocate groups.

29. The professional provider associations, in cooperation with the DHRS, should develop model contracts for medical directors in skilled nursing facilities.

COST OF CARE

The Secretary of the DHRS on September 14, 1975, formed a departmental task force to study medicaid problems and recommend solutions. In part, this task force was charged with examining in detail the system of medicaid payments to nursing homes and making recommendations for programmatic changes. Although its interim report was made on December 15, 1975, it appears that most of the findings and conclusions of this task force are still in the formative stages.

The subcommittee compliments the DHRS on this initiative and urges that the issues generated by the findings and recommendations of the task force receive thorough examination and consideration.

On a more limited scale, the subcommittee examined the issue of the cost of nursing home care which now requires an allocation of $70 million of county, State, and Federal funds per year. It determined that conclusions respecting what the actual cost of care should be are illusive in that data on this subject is often speculative, dated, incomplete, or lacking in appropriate documentation. The DHRS has at its disposal a considerable volume of information for purposes of determining medicaid rates of payment. This information, however, is usually unaudited and therefore potentially inaccurate for purposes of planning and policy development.[48] Moreover, the information now required in cost reports is insufficient for purposes of acquiring an adequate concept of the ownership and financial status of a facility.[49] These and other problems made this line of inquiry especially complex for the subcommittee. However, given this context, the subcommittee found the following:

—The DHRS has established for conceptual purposes a cost model for nursing homes which upon refinement could be of substantial value for budgetary and legislative planning.

—Cost reports submitted to the DHRS are, in most cases, unaudited.

—Reimbursement rates for nursing homes are determined on the basis of an annual cost report. Nursing homes must absorb losses for one year in order

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[45] Testimony of Dr. Vernon Astler on Nov. 14, 1975.

[46] Letter from John E. Pipes, director, Office of Long-Term Care Standards Enforcement, DHEW region IV, to subcommittee staff which indicates that between October 1974 and June 1975 an average of 8.2 percent of nursing homes surveyed were deficient with respect to documentation of medical findings and physicians' orders. An explanation of the term "deficiency" indicates that "it does not mean that the condition or standard [of regulation] was not met, it means only that there was a deficiency of some nature on the 2567 [a form used by the DHRS for reporting deficiencies to the DHEW]."

[47] The Florida medical association (FMA) has advised the subcommittee that it plans to create a special committee to examine long-term care in Florida and make recommendations about how to improve the current system. The FMA is also organizing seminars around the State to address the subject of the role of the medical directors in a skilled nursing facility.

[48] Audits of nursing homes may be performed by the DHRS when indicated; however, as of Oct. 17, 1975, only one such audit had been released.

[49] The subcommittee does not suggest that this absence of data indicates wrongdoing on the part of the nursing home industry or the DHRS. It does suggest that further analysis and modification of cost reporting systems are clearly indicated.

to justify increases in rates of payment. Such losses may have to be borne by nonmedicaid patients.

—Alternative care (e.g., home health services) constitutes less than .02 percent of the medicaid dollars spent in Florida.[50]

—A uniform system of cost accounting is not observed by nursing homes.[51]

—Full and complete disclosure of ownership is not required under present cost reporting procedures, which thereby makes possible less than "arms-length" arrangements between nursing homes and their vendors.

—There are no auditors exclusively assigned within the DHRS to nursing homes. A great need exists for a more vigorous and determined audit program for nursing homes in order to insure that tax dollars are properly expended for services received.

—Contributions to nursing homes from family or friends of medicaid patients are not permitted if they are (a) coercively solicited, or (b) intended to supplement expenses of a particular patient which are covered under a medicaid agreement. The intent of this policy is to insure that money available to a particular patient is regarded as income for purposes of defraying medicaid costs for that patient.[52] However, evidence received by the subcommittee indicates that in some cases such "contributions" are in fact being required as a prerequisite to or condition of admission or continued residence in a nursing home.

As a consequence of these findings, the subcommittee recommends:

30. Rates of payment to nursing homes should be determined on the basis of cost reports submitted quarterly or semiannually rather than annually.

31. All medicaid cost reports submitted by nursing homes to the DHRS should be prepared by a certified public accountant. CPA's so engaged should be fully independent of home management and operations and should not have, nor be committed to acquire, any direct financial interest or material interest in the ownership or operation of the nursing home.

32. Any nursing home, upon application for licensure, should inform the DHRS of the names and addresses of the owners of the facility if a proprietorship and if a corporation or trust, the names and addresses of the directors and officers of the firm. Each person having directly or indirectly 10 percent or greater ownership interest in the facility should be separately identified. Furthermore, if the owner, officer, director, or stockholder identified above has any ownership interest in a related organization providing goods or services to the facility, he or she should at the time of application indicate the degree of interest or control in such related organization. Any change in the ownership status of a nursing home or a related organization as described in the above sentence should be reported to the DHRS.

33. It should be unlawful to offer or receive money of other consideration for the referral of clients, patients, or customers under the medicaid program.

34. All nursing homes certified for medicaid should adopt a uniform system of financial accounting.

35. Penalties should be provided for failure to file a cost report on time or for erroneously prepared cost reports when error exceeds, for example, plus or minus 10 percent of the correct figures.

36. The DHRS should develop a system of medicaid reimbursement to nursing homes which enables homes given a higher performance rating (see recommendation 7 under regulation on p. 14) to receive a higher rate of payment.

37. The DHRS should develop for submission to the legislature a report on alternative reimbursement systems (e.g., prospective reimbursement and bidding systems) by which nursing homes can be provided incentives to improve management efficiency and quality of patient care at a reasonable cost.

38. Competitive bidding for provider contracts should be considered in areas having excess beds.

39. Kickbacks, rebates, or excessive discounts between nursing homes and vendors should be prohibited by law.

40. Guidelines should be prepared by the DHRS to provide interpretations of financial accounting, statistical, and reporting requirements. District seminars should be conducted to educate nursing home personnel about regulatory requirements.

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[50] Annual report of the Division of Family Services, 1973–74.

[51] A uniform Chart of Accounts for Long-Term Care Facilities has been published by the American Health Care Association (formerly the American Nursing Home Association).

[52] See Florida Medicaid Nursing Home Manual, pp. 19–20.

41. It should be required that appropriate records of any related organization (e.g., corporation, partnership, joint venture, etc.) having a controlling interest or exercising managerial control of a nursing home be open to and made available in the State of Florida for inspection by DHRS representatives.

42. The solicitation or receipt or charges to a medicaid patient over and above the rates established by the State and soliciting or receiving any gift, money, or donation or other consideration as a precondition of admitting or maintaining a patient in a long-term care facility should be prohibited.

43. The medicaid reimbursement lag should be reduced by processing of bills and issuing warrants in Tallahassee.

COMMUNITY RELATIONS

As noted earlier, nursing homes have not been widely regarded as a central component of the health delivery system. Likewise, they have often been estranged from their own communities so that the voluntary resources (e.g., volunteers, special programs, etc.) normally available to human service organizations have not been forthcoming.

In 1975 the legislature passed on act which was designed in part to remedy this problem.[53] This act established at both the State and district levels a nursing home ombudsman committee whose primary purpose it is to "receive, investigate, and resolve complaints against nursing home facilities."[54] A secondary policy objective of this act was to bring the industry and the community in closer contact in order that each may benefit from the concerns and problems of the other.

Steps remain to be taken to encourage the further development of improved community-nursing home relationships. These steps are suggested by the subcommittee's findings in this area:

—Information at the community level is lacking about what nursing homes are available, whether these homes accept medicaire/medicaid patents, what special services are provided in which facilities, and comparative costs of homes.

—Results of inspections are inaccessible or unintelligible to most consumers of nursing home services.

—Few consumers or their relatives are aware of how they might inform the appropriate authorities about their concerns respecting nursing home care.

—Local community groups which traditionally work to improve the conditions of less fortunate citizens rarely become involved in enhancing the lives of nursing home residents.

—Volunteers seldom devote their energies to residents of nursing homes because such homes are regarded as businesses in which donated labor simply increases profits for the owner and replaces paid personnel.

—Nursing homes at times discourage visitation by relatives and friends of residents because these visits interrupt normal procedures and take up staff time.

In consideration of these findings, the subcommittee recommends:

44. On a district basis, DHRS should compile for public circulation a current list of nursing homes available and their:

(a) Medicare/medicaid provider status,
(b) special services available, and
(c) comparative costs.

45. Results of inspection surveys, including deficiencies found, should be promptly forwarded to the appropriate district nursing home ombudsman committee and at least one public library or, in the absence of a public library, the county seat in every county.

46. The availability of the nursing home ombudsman committee program, its purpose, and authority should be widely advertised in the media.

47. Nursing homes should maintain as public information records containing copies of all financial and inspection reports pertaining to the facility that have been filed with or issued by any governmental agency. Copies of such reports should be retained in said records for 5 years from the date the reports are filed or issued.

48. A summary of the most recent inspection report, including deficiencies, in form and content specified by the DHRS should be posted in a conspicuous location in every facility.

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[53] See sec. 24–35 of chapter 75–233, Laws of Florida.
[54] *Ibid.*

49. The State level nursing home ombudsman committee and, where possible, district committees should establish advisory committees composed of independent health care advocacy groups such as the Florida division of the American cancer society and the Florida heart association and the principal organized religious groups in Florida to encourage their involvement with and commitment to the aims and objectives of the nursing home ombudsman program.

PATIENTS' RIGHTS

The legal rights of nursing home patients are set forth in general terms under Federal regulations governing nursing home certification.[55] Unfortunately, compliance with these particular regulations is difficult to assess under present procedures because they require knowledge of the intangible consequences of day to day patient care. Furthermore, the extent to which patients' rights are secured depends upon the basic attitudes of staff toward the residents of their facility.

Such problems of enforcement could be dealt with more effectively if the emphasis of inspections were to be placed upon a greater degree of direct interaction between inspectors and patients than is present at this time.

Despite such regulatory problems, the issue of to what basic rights a nursing home resident is entitled remains central to the broader charger of this subcommittee; with respect to this issue the subcommittee found:

—Basic human rights of residents are not fully protected in all nursing homes because nursing homes, like many residential institutions, may allow freedom to be compromised in the interest of orderliness.

—Many nursing home residents are unaware of the rights to which they are entitled and therefore fail to fully exercise such rights.

—Physical restraints are sometimes used in nursing homes to control difficult to manage residents. In most but not all cases such restraints have been ordered by physicians as a part of medical treatment plans.

—The State, through its executive agencies, is not forcefully insuring that the rights of nursing home residents are fully protected.

—The rights of residents are not clearly enumerated in any convenient form. This suggests the need for statutory reaffirmation of patient rights.

The Subcommittee therefore recommends that:

50. A statement of patients' rights should be stipulated by statute. This statute should include at least the following:

(a) Every patient's civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and the facility shall encourage and assist in the fullest possible exercise of these rights.

(b) Every patient shall have the right to have private communications and consultations with his or her physician, attorney, and any other person.

(c) Every patient shall have the right to present grievances on behalf of himself or herself or others to the facility's staff or administrator, to governmental officials, or to any other person without fear of reprisal, and to join with other patients or individuals within or outside of the facility to work for improvements in patient care.

(d) Every patient shall have the right to manage his or her own financial affairs, or to have at least a quarterly accounting of any personal financial transactions undertaken in his or her behalf by the facility during any period of time the patient has delegated such responsibilities to the facility.

(e) Every patient shall have the right to receive adequate and appropriate medical care, to be fully informed of his or her medical condition and proposed treatment unless medically contraindicated, and to refuse medication and treatment after being fully informed of and understanding the consequences of such actions.

(f) Every patient shall have the right to have privacy in treatment and in caring for personal needs, confidentiality in the treatment of personal and medical records, and security in storing personal possessions.

(g) Every patient shall have the right to receive courteous, fair, and respectful care and treatment and a written statement of the services provided in the facility, including those required to be offered on an as-needed basis.

(h) Every patient shall be free from mental and physical abuse and from physical and chemical restraints, except those restraints authorized in writing

[55] Federal Register, Vol. 39, No. 193, Thursday, Oct. 17, 1974, pp. 35775–35776.

by a physician for a specified and limited period of time or as are necessitated by an emergency, in which case the restraint may only be applied by a qualified licensed nurse who shall set forth in writing the circumstances requiring the use of restraint and in the case of use of a chemical restraint, a physician shall be consulted within 24 hours.

(i) This statement of rights should include a statement of the facility's regulations and an explanation of the patient's responsibility to obey all reasonable regulations of the facility and to respect the personal rights and private property of the other patients.

Each facility should give a copy of the statement of these rights to each patient at or prior to the time of admission to the facility or to the appointed personal representative at the time of appointment and to each member of the facility's staff. In addition, each facility should prepare a written plan and provide appropriate staff training to implement each patients' right included in the statement. Regulations should be promulgated by the DHRS to provide methods by which it may be determined that exercising these rights is in no way prevented or discouraged in a nursing home.

ALTERNATIVES TO INSTITUTIONALIZATION

An examination of alternatives to institutionalization was established as one of the initial objectives of the subcommittee. A similar yet more detailed treatment of this subject is now underway in the Florida Senate Committee on Health and Rehabilitative Services in preparation for the 1976 session of the legislature. To avoid duplication of effort, the Senate committee assumed the lead in undertaking the study of alternatives to institutionalization while this subcommittee concentrated its attention on nursing home care.

The reports of the two committees, therefore, will complement one another and together will provide a complete picture of options for long-term care of the functionally impaired.

In anticipation of a more comprehensive Senate report, the subcommittee confines itself to the following general findings in this area:

—There is no alternative to nursing home care for those individuals who, for health reasons, require 24-hour personal care and observation.[56]

—Most people prefer to live out their remaining years at home.[57]

—An estimated 30 percent of those low income elderly persons in nursing homes would not be there if effective community-based services had been available at the time those persons entered nursing homes.[58]

—Appropriate levels of care must be based on an individual evaluation and the availability of acceptable alternatives.

—There is no exhaustive listing of those programs defined as alternatives to institutionalization. A comprehensive alternative care program could include: information and referral services, foster care, home health care, homemaker services, legal services, day care, home delivered and congregate meals, chore services, employment services, transportation, counseling, telephone reassurance, day hospitals, etc.

—The evidence is unclear as to whether a program of alternatives would be less or more costly than nursing home care.[59]

—Home health services are widely regarded as a critical element of any program of alternatives, yet expenditures for this service have been exceedingly low under the medicaid program.[60]

—Alternative programs should be community-based. Community support is encouraged under the structural and funding mechanisms of the Older

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[56] Testimony before the subcommittee on Dec. 13, 1975, by Norma Lemberg, area aging coordinator of district 11, DHRS.

[57] In a survey conducted in Hillsborough County in 1970, "Eighty-five percent of the impaired aged questioned, regardless of whether they were residents of nursing homes or still at home, said they preferred to live out their remaining years at home." (Testimony submitted to the subcommittee on Dec. 13, 1975, by Dr. William G. Bell, director of the Social Policy and Aging Program of the Department of Urban and Regional Planning at Florida State University.)

[58] *Ibid.*

[59] A recent study reported in the Health Resources News (a DHEW publication) found that under certain conditions day care for adults can be more expensive than nursing home care. (See "Adult Day Care Project Completed," Health Resources News, Nov. 1975, p. 2.)

[60] The 1973–74 Annual Report of the DHRS Division of Family Services indicated that less than .02 percent of the dollars expended through the medical assistance trust fund went to pay for home health services.

Americans Act. Community support is essential to insuring that the special needs of an area are met and that continuing funding is available.[61]

Based upon these findings, the subcommittee recommends the following:

51. The DHRS should examine the potential for developing total care programs for the elderly of the campus or village type, which use the nursing home as a core service around which a constellation of other services are organized, that enable an elderly person to maintain an independent style of life for as long as possible.

52. The legislature passed the Community Care for the Elderly Act in 1973. In part the intent of this act was "to diminish the rate of inappropriate entry and placement of functionally impaired elderly persons in nursing homes and related health facilities." (Section 409.3622, Florida Statutes.) This act provides a viable means by which to establish a pilot program of alternative care. The Community Care for the Elderly Act should receive an appropriation adequate for the implementation of a modest level of the demonstration program for which it calls. (See appendix D.)

53. In selected areas of the State, several nursing homes should be established and managed by the State for the purpose of providing:

(a) Beds in areas of critical shortage;

(b) first-hand information about operating costs; and

(c) practical education for students in ancillary health service careers such as:

(1) nursing home administration,
(2) accounting,
(3) geriatric nursing,
(4) geriatric medicine,
(5) geriatric social work,
(6) dietetics, and
(7) other related technical and health-related careers.

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[61] The Minneapolis Age and Opportunity Center, Inc., of Minneapolis, Minn., is an example of a comprehensive alternative care program in a major metropolitan area. An equally successful program relying on community involvement in a medium-sized city is located in Athens, Ga., under the Athens Council on Aging. Both programs rely on Federal funds for the basis of their support but are heavily dependent on the support of the community for matching funds.

Appendix 2

STATEMENTS SUBMITTED BY THE HEARING AUDIENCE

During the course of the hearing, a form was made available by the chairman to those attending who wished to make suggestions and recommendations but were unable to testify because of time limitations. The form read as follows:

DEAR SENATOR CHILES: If there had been time for everyone to speak at the hearing on "Health Care for Older Americans: The 'Alternatives' Issue," in Tallahassee, Fla., on November 23, 1977, I would have said:

The following replies were received:

P. JACK CARROLL, TALLAHASSEE, FLA.

Thank you for this opportunity to bring this to your attention.

As you know, the 1976 Community Care for the Elderly Act, passed by the Florida State Legislature, was the most important piece of legislative action pertaining to the elderly in the last several years.

As you also know, this would provide day care for the frail elderly, home finders, care in the home for the elderly and, most important, multipurpose senior centers, which covers many things—among them health services for the elderly.

In the 1976 legislature, they did not, unfortunately, fund this act. We were, however, successful in getting $1½ million appropriated for this act in the 1977 session. This created funding for the six demonstration units that were operating.

It has been proven, since the 1976 act was passed, that it has been most successful, and has done more good as far as the elderly are concerned; that it has been justified, and more assistance is needed throughout the State to give all elderly the opportunity to participate in it.

Therefore, I would ask you to make every effort to see that the State of Florida is well funded with title V money—money for construction of existing buildings to use as senior centers.

As you know, this is money to create facilities, to have these multipurpose senior centers throughout the State.

THERESE DOWD, TALLAHASSEE, FLA.

Transportation is one of the most needed preventive aspects of care for the elderly. Once an individual cannot go to the store, etc., and the family and the volunteers are tired then he/she is stranded and deterioration of function increases at a rapid rate.

I am supervisor of a project for the elderly (mental health day treatment) and our project is in jeopardy because we have to depend on others for transportation. It is through goodwill that we continue to have the services of a community action program van but it is always 1 hour late and I cannot affect a change in that because it is a service for the whole community. We need a dial-a-bus service here for the elderly, something they can direct themselves. Depending on goodwill of volunteers is not dependable.

Also, I am very concerned about training. It is fine to say to have aging and adult workers go do an assessment, but it requires skill to assess. Medical doctors are not informed about needs of the elderly and I have found some of them to be dangerous, either because of attitudes or lack of information.

I would like to comment that I did not know about the hearing until 8:40 am. November 23, 1977. The community for sharing the news among the elderly is frequently closed mouthed.

Thank you for coming to Tallahassee.

I. BARNETT HARRISON, M.D., TALLAHASSEE, FLA.

There should apparently be legislative provision for Federal loans for construction of church sponsored or other nonprofit retirement centers employing the "full care" concept. A health center or nursing home component of such facilities would minimize problems of repetitive displacement for people as they move from independent living to total dependency.

Presbyterian Homes of Florida, Inc., is currently planning to build such a facility in the Tallahassee area. Although there is documented need, the project has been stalled because of problems acquiring a loan for capital expenditure through conventional sources.

Access to Federal loans would be of great help to the church as it attempts to carry out a ministry of concern for our aged citizens.

ELLEN KERR, TALLAHASSEE, FLA.

Preventive medicine is the issue I stress for all of us, and for the elderly retired person in particular. Obviously, it would cut into the profits of doctors. So what? Are they human beings, or just robots with itching palms?

I have personally known retired persons here in my apartment building who schedule a doctor's appointment whenever they have a new ache in a knee, a back pain, a swelling of the ankle. What follows is the usual examination of heart, blood, urine, chest, another prescription and another fat bill to be paid by medicare.

Preventive medicine might dispel some of our ignorance, push home the danger of obesity, of unbalanced nutrition, of too little exercise.

Let's shame our great American medical profession into it.

R. J. RODRIGUEZ, TALLAHASSEE, FLA.

Many of the speakers mentioned that the programs existing today are guided toward low-income individuals and families. They also stated that a more universal approach was needed. I am a member of a Spanish minority in this State. I have worked with the Spanish elderly in Dade County. It is my feeling that many of the Hispanic elderly in Florida and many other States are not being reached by these programs. Programs with bilingual components are badly needed in this State in order to reach this section of the population that constitute a great number of older Americans in Florida.

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