S. Hrg. 101-398

LONG-TERM CARE IN RURAL AMERICA: A FAMILY AND HEALTH POLICY CHALLENGE

JOINT HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING

AND

THE PEPPER COMMISSION
UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

LITTLE ROCK, ARKANSAS

AUGUST 22, 1989

Serial No. 101-8

Part 6

Printed for the use of the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE
23-442 WASHINGTON : 1990

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

SPECIAL COMMITTEE ON AGING

DAVID PRYOR, Arkansas, *Chairman*

JOHN GLENN, Ohio
BILL BRADLEY, New Jersey
QUENTIN N. BURDICK, North Dakota
J. BENNETT JOHNSTON, Louisiana
JOHN B. BREAUX, Louisiana
RICHARD SHELBY, Alabama
HARRY REID, Nevada
BOB GRAHAM, Florida
HERBERT KOHL, Wisconsin

JOHN HEINZ, Pennsylvania
WILLIAM S. COHEN, Maine
LARRY PRESSLER, South Dakota
CHARLES E. GRASSLEY, Iowa
PETE WILSON, California
PETE V. DOMENICI, New Mexico
ALAN K. SIMPSON, Wyoming
JOHN WARNER, Virginia
NANCY LANDON KASSEBAUM, Kansas

Portia Porter Mittelman, *Staff Director*
Christopher C. Jennings, *Deputy Staff Director*
Jeffrey R. Lewis, *Minority Staff Director*

THE PEPPER COMMISSION

(U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE)

SENATOR JOHN D. ROCKEFELLER IV, West Virginia, *Chairman*
REPRESENTATIVE FORTNEY PETE STARK, California, *Vice Chairman*
SENATOR MAX BAUCUS, Montana, *Vice Chairman*
SENATOR DAVE DURENBERGER, Minnesota, *Vice Chairman*
SENATOR BILL GRADISON, Ohio, *Vice Chairman*

REPRESENTATIVE LOUIS STOKES, Ohio
REPRESENTATIVE THOMAS TAUKE, Iowa
REPRESENTATIVE HENRY WAXMAN, California

SENATOR JOHN HEINZ, Pennsylvania
SENATOR EDWARD M. KENNEDY, Massachusetts
SENATOR DAVID PRYOR, Arkansas

PRESIDENTIAL APPOINTEES

JAMES BALOG
JOHN COGAN
JAMES DAVIS, M.D.

STAFF MEMBERS
Judith Feder, PH.D., *Staff Director*
Edward F. Howard, *General Counsel*

CONTENTS

CHRONOLOGICAL LIST OF WITNESSES

APPENDIX 1

APPENDIX 2—WRITTEN COMMENTS FROM HEARING AUDIENCE

LONG-TERM CARE IN RURAL AMERICA: A FAMILY AND HEALTH POLICY CHALLENGE

TUESDAY, AUGUST 22, 1989

U.S. SENATE,
THE PEPPER COMMISSION
AND THE SPECIAL COMMITTEE ON AGING,
Little Rock, AR.

The committee met, pursuant to notice, at 10 a.m. at the Grand Ballroom of the Excelsior Hotel, Little Rock, AR, Senator David Pryor presiding.

Present: Senator David Pryor and Dr. Jim Davis.

Also present: Portia Porter Mittelman, staff director; Christopher C. Jennings, deputy staff director; Kris Phillips, press secretary; Fanny Neely, legislative correspondent, Special Committee on Aging; Edward Howard, general counsel; Steve Edelstein, professional staff; and Phil Shandler, professional staff, Pepper Commission.

OPENING STATEMENT OF SENATOR DAVID PRYOR, PRESIDING

Senator PRYOR. Good morning, ladies and gentlemen. We had not anticipated an overflow such as this, but we are very, very proud to have all of you here to demonstrate your interest in this very touching subject that all of us will be talking about this morning for the next 2 hours.

Today, Dr. Jim Davis and I are pleased to convene the joint Pepper Commission/Senate Special Committee on Aging hearing dealing with the issue of long-term care in rural America. For those of you who do not know Dr. Davis, who is right here on my right, Dr. Davis is the immediate past president of the American Medical Association. He is also an appointee by former President Ronald Reagan to serve as one of the three Presidential appointees to the Pepper Commission. The Pepper Commission, if you don't know, is the U.S. Bipartisan Commission on Comprehensive Health Care. It was established this year to develop proposals to address the problems of the 31 million Americans without insurance and the lack of long-term care protection. The Commission has six Senate members, six House members, three Presidential appointees; Dr. Davis is one. Our report to Congress of this Commission is due March 1, 1990. I am pleased to be a member of the Pepper Commission.

Considering the extraordinary witnesses and the audience that we have assembled before us, there is no question that we will have a productive and an interesting hearing. No hearing, however, could be a success without the assistance of many dedicated and hard-working individuals; today's hearing is no exception.

And before we go to the very important subject at hand, I would like to recognize a number of people. First Mary Lou King, public relations liaison, Division on Aging for her assistance with the development of today's hearing, including the setup of this room. Herb Sanderson, the deputy director, Division on Aging. He lent tremendous support, as did his staff. Ann Wasson, executive director of the Arkansas Association of Area Agencies on Aging. Senator Jay Rockefeller of West Virginia, who chairs the Pepper Commission who could not be present with us today. He sends his best wishes and his fine staff, Ed Howard, Steve Edelstein, and Phil Shandler. I think that we have, hopefully, one or two of those staff members here. Jeff Kirsch, District of Columbia Long-term Care Campaign, Herb Bingaman and Scott Holladay, Arkansas Seniors Organized for Progress, Cassandra Wilkins, State Office on Disability, each of whom provided assistance in locating our first panel of witnesses.

The In-Home Services Division of the Arkansas Department of Health, Area Agency on Aging, Southeast Arkansas, the Central Arkansas Area Agency on Aging, East Central Arkansas Economic Development Corporation, East Arkansas Area on Aging, Ingrid Khanton, the Management Project Analyst, Division on Aging. She assisted in the preparation of the charts and graphs that we have this morning.

The following provided written testimony which will be made a part of the record and which will go into the official Pepper Commission transcripts and will be shared with our colleagues as we deliberate our recommendations before the March 1990 recommendation to the U.S. Congress. Drs. David Lipschitz and Ronnie Chernoff, VA Medical Center; Billie Larch, executive director of Arkansas State Nurses Association; Lynn Zeno, executive director of the Arkansas Medical Society; Keith Kennedy, member of Guardian Advisory Counsel, NFIB.

Just as we could not put together a hearing like this without everyone pitching in, today's forum will show us, as a society, that we cannot adequately care for our chronically ill without an all-out team effort from the family, the private sector health care providers and insurers, Federal, State, and local governments. We all know that the family caregivers are more than living up to their end of the bargain. But in a team sport, one superstar rarely, if ever, reaches the victory circle without the supporting cast of players to back them up. While the other players are in place, many have questioned the adequacy of their support today.

As we will see, chronic illness and the people it affects knows no age, sex, race, or income boundaries. The need for long-term care is, therefore, a family health care issue that touches and should concern all generations of Americans.

This morning, we will hear how chronic illness not only strikes millions of elderly persons, but targets the non-elderly as well. In fact, 3.6 million Americans today or 39 percent of America's chronically ill population is today under the age of 65.

Most of this population will do anything, including foregoing needed care in order to stay at home. In fact, as the first chart shows, of the 9.3 million Americans of all ages who need long-term care services, 7.6 million or 82 percent reside in the community or in the homes.[1] And because Medicare and most private insurance plans do not offer significant long-term care coverage, the lion's share of the care is delivered, yes, by the family. In fact, as the next chart shows, 74 percent of the chronically ill receive their care solely from family and other informal sources.[2]

Who are these heroic caregivers? Well, one, she is your next door neighbor, age 78, who continually provides care to her bedridden husband in the face of the greatest of physical, emotional, and financial needs. He is your middle-aged Sunday School teacher who, at a time when he is trying to find the money to finance his wife's retirement and his, help with his children's education, he discovers suddenly that he will have to find some way to care for his diabetic wife and his Alzheimer's disease-afflicted mother.

They are the parents who you rarely see at the PTA meeting because they are taking care of their youngest child who has been diagnosed with multiple sclerosis and, because he works and has a job that does not offer health insurance, they have too much money to qualify for State assistance and too little money to afford an individual private health insurance policy. These are the hundreds of thousands of American families who today are falling through the cracks.

These families don't want handouts. Except in the worst cases, they want and, in fact, insist on being the primary caregiver of their loved ones. All they want is some assistance to help keep their sick family members out of the nursing home and away from the hospital. Without this help, the caregivers of today oftentimes become the care recipients. They will go without adequate food, clothing, personal time and, over time, this exacts its own toll. The people need assistance with the costs of home and community-based care, nursing home care, and the spiraling costs of prescription drugs.

Well, what's gone wrong with the prices on prescription drugs? In the case of the elderly—listen to this—four out of five persons have one or more chronic conditions that require prescription drugs. Consistent with this, over 80 percent of the top drugs most frequently prescribed for the elderly are given for the treatment of the chronic conditions. Because of the importance of these drugs to the chronically ill elderly, it is easy to understand today why I believe the new Medicare prescription drug benefits can and should be described as a long-term care benefit.

Research just completed for the Department of Health and Human Services found that drug costs are an even more significant factor in bankrupting the chronically ill than home care costs. This fact may astound some people here, but it does not surprise me. Last month, the Special Committee on Aging held a hearing. We asked the top 20 drug manufacturers of America to come in and testify. None of them testified. They were afraid to show their exorbitant profits and, in my opinion, were also ill-equipped to defend, in my opinion, the greed that they have practiced. The elderly often have to make tough decisions between purchasing the home care they need and the prescription drugs they need. Usually, they

---

[1] See appendix, p. 97.
[2] See appendix, p. 98.

decide to purchase the medications and sacrifice their other desperate need, the need for home care.

What's more, the financial burden of these drugs is increasing and causing more problems. Between 1981 and 1982, the general inflation rate that our country has experienced was somewhere in the neighborhood of 28 percent. During that same period of time, and this chart will indicate this, the same period of time 1981 to 1988, the prescription drug price increases were a staggering 88 percent.[3] Can the drug manufacturers defend this price escalation? The answer is no.

These increased costs with the proliferation of drugs that do little more than duplicate what is already on the market threaten not only the newly enacted Medicare prescription drug benefit, but also the health and well-being of the elderly. Increased costs create incentives for the elderly to not follow their doctor's prescription. In order to save money, they stretch money, they stretch out medications and take them only when they "feel bad." Such inappropriate use of these prescriptions leads to more health problems and contribute to unnecessary, expensive hospitalizations and nursing home placements.

The title of this hearing this morning, held jointly with the Committee on Aging of the Senate and with the Pepper Commission, is entitled "Long-Term Care in Rural America." I wanted to hold this hearing here to make certain that the Pepper Commission and the Aging Committee members would have access to the information that showed that, like most everything else, you cannot develop effective policy without learning about the special populations that you will be affecting. Delivering long-term care in rural areas will, out of necessity, require different and creative approaches that may be used in the urban areas of America.

Rural America is not a carbon copy of urban America. As the chart behind me illustrates, while the elderly comprise 12 percent of the total of the U.S. population, they account for more than 25 percent of the population of rural America.[4] The rural elderly are twice as likely to be poor than their urban counterparts. Difficulties from personnel and inadequate transportation further exacerbate the problems which face rural areas attempting to address the needs of their chronically ill residents of all ages.

Well, today, folks we are faced, really, with two choices. We could moan, we can groan about the costs, say it's too difficult a problem to even begin to address. Or we can, in fact, work toward developing a cost effective, creative responsive and caring program to better address the problems of our chronically ill.

I am not going to sit back and continue to passively listen to the stories that we'll be hearing today. I'm ready to do something about them. In fact, in April of this year, I was pleased to join the chairman of the Pepper Commission, my colleague, Senator Jay Rockefeller, in introducing S. 785, the Medicaid Home and Community Care Options Act of 1989. Under this bill, it states the States would be given the option to extend Medicaid coverage for home

---

[3] See appendix, p. 99.

[4] See appendix, p. 98.

care services, to low-income, disabled persons over the age of 65 without the usual harsh restrictions.

Today, we will hear what other segments of the Federal, State, and local governments are attempting to do with the limited resources available. We're also going to hear what our friends to the north in Canada are doing, with their very innovative approaches to addressing the long-term care challenge.

Let me—before I move to our next segment, let me state this. Many of you may have come to the hearing today with a personal problem that you have or a situation where you, too, have fallen through the cracks. If that is the case or if you have, let's say, a constituent case work matter that you would like to bring to the attention of my office or the Pepper Commission or the Committee on Aging, we're going to set up—after the hearing is over in the Doyle Rogers room immediately out these doors, we will have four case workers who will be there to assist you in dealing with your particular situation. That will be in the Doyle Rogers room immediately out of these doors.

Also on your chairs, we have provided for you comment sheets. As you can see from the size of the audience today, it would be totally impossible for us to allow each person to get up and give a comment. We would probably be here into the year 1990 if we did that. But what we have provided is a piece of paper. And we have tables as you leave the ballroom this morning, as you leave, make any comments. We would appreciate—if you don't mind, this is not necessary, of having your name and your mailing address. And we will certainly want to read those comments and hopefully, you might give us some suggestions on what we might do.

Let me introduce my colleague here this morning, and he comes from the State of North Carolina. Dr. Jim Davis is making one of his rare trips to the State of Arkansas. We welcome Dr. Jim Davis. Jim.

OPENING STATEMENT OF DR. JIM DAVIS

Dr. DAVIS. Thank you, Senator Pryor. Let me say what a genuine pleasure it is to be in Arkansas. Not every North Carolinian has this opportunity, and I'm delighted to be able to avail myself of it. Let me thank every one of you for being here today to listen with us and to speak with us about the question of long-term care. Let me tell you that this is a major issue in the minds of every physician in this country and physician organization such as your State Arkansas Medical Society, the American Medical Association, and others. This is a problem that we have got to work on together, as Senator Pryor has said, to solve. This country has got to do something about long-term care. I thank each of you for being here today. We welcome your comments. And in the interest of time, Senator, I will stop at that point.

Senator PRYOR. Jim, thank you very, very much, and we welcome you to our State of Arkansas.

Well, y'all are getting ready to do a first here. How many of you have ever previewed a movie for the first time? I don't know if any of you have. I have not, but you are getting ready to. This is an 8-minute segment, ladies and gentlemen, of a film that's narrated by

Walter Cronkite. It will air in October over the Public Broadcasting System's network. The film is entitled "Can't Afford to Grow Old." It's going to touch on some of the issues that we will be discussing in this hearing this morning.

And for the record, I would like to ask that a letter from Walter Cronkite dated August 17 to me—it says, "Dear David—" he wouldn't know me from Adam, but it's nice for him to call me that.[5]

"Thank you for your invitation to speak on the long-term care issue in Little Rock August 22nd. As you know, my hectic travel schedule is not going to allow me to be there. In any case, I hope this film helps to give this issue the credibility it deserves." And I can't think of a better audience to preview Walter Cronkite's new film that he is narrating. And so it's 7 to 8 minutes, and I would ask now that the lights go down.

(At this time, a segment of above-referenced film was shown.)

Senator PRYOR. I need this microphone on here. Is there a good electrician in the house, retired or otherwise?

Well, we could call the Razorbacks or something, call the hogs or something. Thank you. Are we working now? Great. Thank you very much.

Well, ladies and gentlemen, we have seen a few moments of the segment of the film which will be shown in October—that was an 8-minute segment. Just as we have seen that segment of those people on film, we now bring to our witness table four individuals who are in a very similar category to this couple trying to care for a very dependent individual. And I would like to ask our first panel of witnesses today to come forward and tell their story and then we might have a few questions for them. I am going to ask for Mary Anita Andrews, Velma Gilbert, Debra Nelson, Edrell Trickle, if they would come forward.

Chris, for Mrs. Trickle, we will need the mike taken over to her. OK. Velma Carter, I believe—Velma Gilbert is next and Debra Nelson. Let me tell you a little about these four very courageous individuals.

Mary Anita Andrews is from Little Rock. She has multiple sclerosis. She is going to share with us her problems of getting the care she needs while maintaining her independence.

Velma Gilbert is from Pine Bluff. Despite health problems of her own, she is the sole caregiver of her mother, who suffers from dementia, glaucoma, and diabetes.

Debra Nelson is from North Little Rock. Her daughter, Jennifer, has cystic fibrosis. I believe that she is age 11. Mrs. Nelson will describe what this chronic illness has meant to their family.

Mrs. Edrell Trickle is from Blytheville in Mississippi County. She is going to tell us how placing her husband in a nursing home is threatening to send them today into bankruptcy. Folks, these are great women. Let's give them a hand.

Senator PRYOR. I know that all of you have a prepared statement for the record. You may read from your prepared statement, you

---

[5] See appendix, p. 100.

may summarize, or you may just tell the story any way that you would like. Ms. Andrews.

STATEMENT OF MARY ANITA ANDREWS OF LITTLE ROCK, AR, NURSING HOME RESIDENT

Ms. ANDREWS. Good morning. My name is Mary Anita Andrews. I am 57 years old, and I have had multiple sclerosis for 41 years. Save your figuring. I was 16 when it struck, and I didn't get too bad, was able to finish high school and, of course, I didn't get to go to college or anything like that, but I was fortunate in that a few years after I got out of high school, I was able to land a job with a radio station and newspaper in my home town, Hope, AR. I worked at home for the paper and for the radio for the next 18 years. I lived with my parents and had a rather active and productive life, all things considered.

By 1980, though, everything had changed. My parents had died several years before, and I was living alone, having increasing difficulty, and I didn't have anybody nearby to take care of me. So I moved to Little Rock to a retirement home.

Senator PRYOR. Excuse me just a minute. Is Ms. Andrews being heard in the audience?

AUDIENCE MEMBERS. No.

Senator PRYOR. All right. Now, if we can put a man on the moon, if we can build a bomber that none of us can see that costs $530 million, we are going to have a mike system that works here.

Ms. ANDREWS. OK. That sounds better. There are approximately 250,000 persons with multiple sclerosis in the United States; many would say more than that. But in Arkansas, we know of 1,000. I am here today to tell you my story about life with MS.

After being stricken with multiple sclerosis at 16 years of age, I was fortunate several years later to acquire jobs with a radio station and newspaper in my home town. I worked from home, where I lived with my parents, and was able to maintain these positions for the next 18 years.

After my parents died, I was having increasing difficulty with MS. I didn't have anyone to fall back on, and living alone and falling occasionally was scarey. So I moved to Little Rock to a retirement home. And would you believe the next year I got married?

But he only lived 3½ years; he had a bad heart. In 1987, while at the retirement home, I broke my leg and was unable to move around. As a result, I developed bed sores, became infected, and I ended up in the hospital for 9 weeks. My leg and the infection healed. But between the hospital stay and the follow-up care, my money was going fast.

I didn't know really what to do except it seemed to me like the only solution was to go to a nursing home. I did. And in less than a year, I was really almost broke. The care I needed would only be paid for by the State if I was in a nursing home. I needed that personal care, and I still do. Every day, I need personal care. My family is either too far away to come help or my health—their health needs were too extensive, and so they couldn't help out. So I just spent practically everything I had left so I could qualify for Medicaid.

It's difficult for me to accept that at my age and with, I hope, my faculties being intact that I belong where I am. It was my choice, though. I shopped around and I picked out what I thought was the best one in town, and I liked the personnel, I like the location. The main problem is many of the people in the facility suffer from severe dementia. And believe me, living 24 hours a day in that situation is devastating.

My monthly Social Security check comes to $353. All but $30 a month I must give to the nursing home. My biggest expense is for medication. While the State's Medicaid program pays for some of the drugs I need, it does not pay for the one I need the most, Liorosal. It costs me $57 a month and I have to pay that either out of my $30 allowance or the $2,000 in my bank account I was allowed to keep when I came in. That account is now down to $1,200, and it can't be built back up. I am not allowed any income whatsoever.

I feel like I'm in a no-win situation with no hope for improvement. I'd like to try to sell some of my writing, but the Government won't allow me to earn any money for this work. I suppose I could write under a pen name and add somebody else to collect any checks I got, but I don't know why the Government makes you lie and cheat in order to earn a few dollars for honest work.

There ought to be a way for a person to maintain some sort of earning income. I'm not saying that I should get all the earnings; some part of it should go back into the Medicaid/Medicare Program. Now, I don't know what percentage the Government should require, but the Lord doesn't expect more than 10 percent.

It's frustrating, to say the least. I'm eligible for an apartment in a HUD-supplemented high-rise building. I'd love to move there, but I can't afford to pay for the daily nursing care I need. I qualify for Medicaid personal care, but not as many hours as I need to live alone. I'm going to continue my efforts to set up a small group home for MS patients that would be a pilot program for the State.

Senator, we would need financial assistance to set up the home for about six people, maintain its operation and provide personal care. Residents would contribute from their own Social Security or SSI checks. A home like this would give us dignity, a sense of well-being, and control over our own lives.

If the money that pays for my nursing home care and for that of the others could be used to help fund a group home, I'd be much better off, the others would, too, and I can't see why that couldn't be made possible.

Can't we do it under the current laws? I don't know. I feel that the emotional trauma I am now experiencing exacerbates my physical problems. You know, MS doesn't usually kill. It does some, but not usually. But living under extreme tension 24 hours a day could certainly do the trick.

Sometimes I feel like I'm entombed and I have no way of getting out. Senator, people who still have their minds should have a better quality of life.

I hope this hearing will contribute toward the development of a much more humane program of comprehensive home care services. This would go a long way toward eliminating the helplessness I feel and the others in my situation feel, also. At my age—well, I hope to live a long time. But most people feel like when you go to a nursing home, it's the last step before the cemetery, and I'm just not quite ready for that trip.

Senator PRYOR. Thank you very much. Thank you, Ms. Andrews. Thank you very much. And now, we will ask Velma Gilbert to tell her story. Velma, if you would hold that mike right up—by the way, they've got a new microphone system on the way from somewhere, so we'll have a better system momentarily. Go right ahead, Velma. Hold it right up to your mouth. Thank you.

STATEMENT OF VELMA GILBERT, PINE BLUFF, AR, CAREGIVER OF HER ELDERLY MOTHER

Ms. GILBERT. Good morning. My name is Velma Gilbert. I am 58 years old, and I live in Pine Bluff with my mother, who is 86 years old. For the past 2 years, I have been my mother's sole caregiver. She suffers from serious dementia, glaucoma, and diabetes. In addition, she has no bladder control.

Caring for my mother has not been easy. It's particularly difficult for me because I have a serious health problem with hypertension. I can never leave her by herself because I'm afraid she may hurt herself. I bathe her, dress her, feed her, and change her diapers.

In the past, I have also tried to work. However, the combination of my job with my own health condition and the physical demands of caring for my mother was more than I could handle.

Although the people at my work were very understanding, I was absent quite a bit. It got to the point where I was no good to my employer and no good to my mother. So I quit in order to be a better caregiver for my mother.

Since then, it's really been a struggle financially. Out of our monthly income of $479, I must pay $70 a month for my mother's prescriptions, about $65 or more for her diapers, and $110 for my own medication. This doesn't leave much for other necessities like food, clothing, and utilities. Yet, it is still too much for us to qualify for Medicaid. And because of this, we are also ineligible for any assistance from the Area Agency on Aging.

The only way my mother could qualify for Medicaid is for her to go into a nursing home. Well, I know there are nice nursing homes and there are nice people also, but I just couldn't stand to see my mother in one. I'd do anything to prevent it.

In fact, that's what I'm trying to do now. With the few dollars we do have, I pay a minimum-wage home attendant to help me in the mornings during the week. What I can't understand is this, why will the State pay over $1,000 a month to pay for my mother's care in a nursing home, but won't even help out with the modest cost of this attendant? My mother and I are just getting by on an income that one healthy individual would find difficult or impossible to do.

Added to all of this, my brother died a few weeks ago and without him around to help us financially and physically, our situation has become more desperate.

Senator Pryor, caring for a person in my mother's condition is a—very difficult and stressful. In a country that has so much I strongly contend that it is not too much to expect home care assistance for our sick and elderly.

As a caregiver, we neglect ourselves taking care of others. Hence, this results in additional strain and stress. On the average, I have been hospitalized twice yearly for my physical condition. Even requesting Meals on Wheels to be delivered to my home daily for my mother has been denied. I requested this so that at midday, I could give her a balanced diet. This would reduce the undue strain on me that results from preparing her meals at this time.

I want to be the best caregiver I can for my mother, but I will be unable to do so without some outside assistance. After years of dedicated service, our parents should be kept in familiar surroundings.

Senator Pryor, I hope my being here today plays a role in helping people like myself get this care.

Senator **Pryor**. Thank you very much, Ms. Gilbert. Debra Nelson.

STATEMENT OF DEBRA NELSON, NORTH LITTLE ROCK, AR, CAREGIVER OF HER CHRONICALLY ILL CHILD

Mrs. **Nelson**. Good morning. I am pleased to have this opportunity to tell you about the problem we have experienced in our ongoing attempt to care for our wonderful 11-year-old daughter, Jennifer.

Jennifer has cystic fibrosis. However, despite our modest income, the fact that we don't have health insurance, and Jennifer's need for expensive care, we have been denied State and Federal medical assistance because we can't qualify for SSI and TEFRA.

We applied for SSI the first time in 1978 and have applied three times since. Even though Jennifer's pharmacy bill for her cystic fibrosis medications the previous year had run over $12,000, we were told her condition was not severe enough to be called disabling.

For most of 1987 and 1988, we were not eligible for any State or Federal program. And although my husband worked during that period, he was not able to obtain a job with insurance coverage. During that 20-month period, we accumulated thousands of dollars of medical bills and got months behind on our bills. We are still over a couple of months behind and owe over $13,000 just for medications and IV home therapy.

Cystic fibrosis is a very disabling disease. It is a disease that takes more physical treatment from the parents and the child than of any other disease I know of. We must begin each day, with no holidays or days off, with an hour of therapy. This is 20 to 30 minutes of breathing medicine in an aerosol, followed by 30 minutes of chest physical therapy. These treatments must be done three times a day when Jennifer is doing well. When she was ill as she was this past spring, they must be done five times a day. To me, the treatments alone make cystic fibrosis disabling to children.

Because of her disability, we had hoped to get some assistance to pay for the expensive care she needs. Everyone but the State views her as being disabled. But because she does not meet the SSI disability standards on the pulmonary function tests, which is comparable to how well you can blow up a balloon, Jennifer has been denied. In other words, just because Jennifer can blow up a balloon on test day, she does not qualify.

In addition, Jennifer has special disgestive problems that all cystic fibrosis patients have. She has almost constant abdominal pain from distal intestinal obstructive syndrome.

Jennifer missed 37 days of school last year, which means she missed one-fifth of the entire year. She has to take 70 pills a day. Can you imagine having to take 10 pills before you could drink a glass of milk or even eat one cookie? In addition to the medication she takes by mouth, she must undergo IV therapy at home for 14 or more days. This therapy calls for $5,500 to over $6,000 each time and is needed once or twice a year. On top of the staggering costs of her drugs and IV therapy, her 20 clinic visits and 2 hospital visits in the past 9 months came to $20,000. The worst part of all the treatments and medicine that kids with CF must take each day is that it will not cure them. It only tries to keep them at the level of health at which they are now. Cystic fibrosis is a progressive disease and can only worsen.

There are several medical programs for children and we have applied for all of them. SSI and TEFRA are based on disability utilizing criteria which eliminates many multiply handicapped children. SSI has financial as well as medical guidelines for qualification. Although our income meets the financial criteria, Jennifer does not meet the medical criteria. TEFRA is a wonderful program that recognizes that some illnesses would be too costly for any family, but the yearly medical costs cannot exceed $15,062.60 for the highest level of care. Jennifer's medical bills can run upwards to $40,000 a year.

Medicaid "spend-down" is another program. You are given a dollar figure, which is approximately 2 months' gross income, that you have to pay and then Medicaid pays the rest for that 3-month period. Then you start over for the next 3-month period. This is helpful, I'm sure, for a family facing a one-time illness, but it would leave us with only $237.73 to live on each month, and our house payment alone is more than that.

Just recently, we qualified for children's medical services. Unfortunately, budgetary constraints forced them to have financial guidelines, as well as medical. When both my husband and I were working to catch up on back bills, we came within $5 a month of being financially ineligible. My husband would like to work more hours, but we have to make sure we do not exceed the financial guidelines and suddenly find ourselves without any source of help. Even if he does work more hours and does qualify for a group insurance plan, it is unclear whether the plan would cover pre-existing conditions.

To me, cystic fibrosis is disabling in any stage of the disease. It takes the same amount of treatments and medications whether the disease is considered mild or severe. I can't imagine anything more disabling than a chronic lung disease and chronic digestive problems and a life expectancy of 24 to 25 years.

It is frustrating to be one of the uninsured of the world and face such staggering medical bills. Senator Pryor, chronically ill children and their families need better care and more compassionate assistance with the cost of long-term care. I am here today representing all children with multiple handicaps, not just my daughter. I hope this hearing helps you help us.

Senator **Pryor**. Mrs. Trickle.

STATEMENT OF MRS. EDRELL TRICKLE OF BLYTHEVILLE, AR, CAREGIVER OF HER HUSBAND, A NURSING HOME RESIDENT

Mrs. **Trickle**. Good morning. My name is Mrs. Edrell Trickle. I'm here to talk with you about how a long-term nursing home stay can literally bankrupt you. I know because over the past several years, I have spent over $60,000 trying to take care of my 86-year-old husband Tobe, who has Alzheimer's disease.

Next month will be our 49th anniversary. Up until recently, we had one of the best marriages anyone has ever had. In all of those years, we just had three fights. Though those were fights——

Senator **Pryor**. You just had three fights in 49 years? That's a miracle, I think.

Mrs. **Trickle**. Three serious fights.

Senator **Pryor**. Serious fights. I stand corrected.

Mrs. **Trickle**. In all those years, we just had three serious fights. Those fights weren't pleasant. I wouldn't mind having one now with him because at least he'd be talking to me. He's not now. The last time he said a word to me was in December. The best I can hope for now is that he recognizes me. Sometimes he doesn't even do that. He just looks through me.

Before I tell you more about what Tobe is like, I would like to say a few words about what he was like. My husband was a hard-working, honest, Christian man who would do anything for anyone. He worked for more than 20 years as a crane operator and a mechanic, and was one of the best, most productive workers you have ever seen.

Together, we worked hard to save money for our retirement. We wanted to make sure we didn't burden anyone, and also wanted to make sure we had some money for what some call the golden years. We planned out everything. We planned out everything except for either one of us coming down with a mind and body altering disease that slowly squeezes the life out of a person. Plain and simple, that is what Alzheimer's disease is and does. The day we knew for sure Tobe had Alzheimer's disease was the end of our dreams, for those times wouldn't be golden.

I tried for a long time to take care of Tobe at home about 5 years ago. A doctor made me put him in a nursing home for the first time. He was such—it was such a hard thing to do. In fact, because I wasn't satisfied with the care he was receiving, I even brought him home once. I would do that, even though I know that I couldn't take proper care of him.

Tobe is now in a nursing home in Missouri just 15 miles from Blytheville. I moved him there because he had to be in a skilled nursing home, and the only one nearby was so expensive.

Also, none of the nursing homes in northeast Arkansas are Medicaid certified. So to use his Medicaid benefits, we had to go to Missouri. Tobe now has to be tube fed. He needs assistance to help his bowels move and requires a catheter. The cost of his care averages $1,500 a month. In addition to that, he has physicians and hospitalization expenses, plus a prescription drug that is more than $50 a month. Last year alone, I spent over $20,000 for his care.

It sure doesn't take long to bankrupt oneself spending $20,000 a year. There are so many bills coming in, I just can't keep up. Sometimes I feel like just giving up, but I can't give up because Tobe needs me. Anyone who has been as good to you as he has been to me deserves to have his wife stick by him. As long as I'm alive, I'll be there for him.

For me, being there means seeing him every day. It's hard for me being away from him even for this hearing, Senator. This man has been my life. Being there for him also means making financial sacrifices. I don't spend money on anything but absolute necessities. And even then, I try to buy those only when they are on sale. The shoes I have on today are over 20 years old. I hardly ever turn on the air conditioner unless it gets over 90 degrees, and I don't even buy meat anymore because—unless the date on the package is about to expire and they have marked it down.

I save every penny I can to care for Tobe. In fact, I'd probably feel guilty if I did spend the money. Just the other day, I wanted ice cream so bad. I saw it at the grocery. But then I thought about Tobe and how bad I might feel if I spent the money on myself. I decided not to buy it.

Even watching every penny, I find myself running out of money. After spending over $60,000 on his care, I have $23,000 left in a CD. We also have a little piece of land that I guess I may have to sell. The trouble is, I can't even get what we paid for it 20 years ago. The additional income coming in is Tobe's $701, my $264 Social Security. His check goes into the bank, but I have to use it to pay for his care. It's hard to believe that covers less than half of the monthly nursing home bill.

I am really worried now. Most people would think they were really well off with $23,000 in the bank, a small plot of land, and a small Social Security check. I figure that all of that will disappear in less than 3 more years in taking care of Tobe. At that point, I'll be bankrupt and, if Tobe is still alive, I will be trying to get by on $264 Social Security.

Senator Pryor, I'm more than willing to do my share. But I'm not in the best of health. The other day, while visiting Tobe on one of his bad days, they took my blood pressure and it was 230/98. My medications for high blood pressure and arthritis cost me around $50 a month. I am just afraid of what will happen to me and how I will take care of myself after we have spent all of our savings.

I just recently learned that the new Medicare law has a section that would protect assets, including savings, and at least $850 of Social Security payments for people like me, who are spending all of their money to care for their spouses. This new law has already helped because it has paid 150 days of nursing care, saving us about $7,500. I was pleased to hear that, but I also learned that there is talk of repealing that law.

Senator, this sounds like a good law. It would give some small protection to those who have scrimped and saved for their retirement. I always thought that was the way we were supposed to do it. I hope that my being here will help you make sure that people like me get this small protection. Thank you.

Senator PRYOR. Thank you very, very much. Thank you. Well, in my opinion, these are four heroic people. I think that you all will agree.

They are also four people who represent probably, as we said earlier, hundreds of thousands of families across our great and rich country that have fallen through the cracks, where the programs either don't work or the income is too high or the ailment is not severe enough. And I have just a couple of questions, I know Dr. Davis may have some. But these, I think, are three classic cases that demonstrate what the Pepper Commission and what the Aging Committee and all of us not only need to hear, but need to address in our recommendations.

Let me just ask a question of all of you and very informally, just chime in. Are there any of the programs today that are working? Do you find that on the State level, the Federal level, the local level, do you find a coordination in the programs, or is it just that the programs don't work, that they don't fit your particular needs and situations? Would anyone like to talk about that? Yes. And if you would just pass the microphone around, please.

Ms. GILBERT. Thank you. The programs work for some people. It's just that if you are $20 or $30 above the guideline, that's where you fail, where you don't get the assistance that you need.

I also understand that there is a backlog in some of the programs, especially the—where you'll get in the meals for elderly people. Now, the van goes right down my street, but there is a backlog on getting Meals on Wheels.

Senator PRYOR. Is this why you were denied the Meals on Wheels?

Ms. GILBERT. At that particular time, they said there was a backlog.

Senator PRYOR. And the van goes right down your street?

Ms. GILBERT. Yes, yes, yes. So people are getting the services, but I understand some services—this is what's happening with that particular service. But the other, I'm just $20 or $30 over the guideline. And you need additional assistance to help you because when you have a person 22 hours—I get someone in the morning to help me. In the mornings when they come in, everything is wet, you know. You just have to just do everything. Well, you have the other 22 hours yourself to try to work with your parent. So that's the problem, if you could get some additional help. This is what I am concerned about.

Senator PRYOR. And did you make a conscious decision not to place your mother in the nursing home?

Ms. GILBERT. Yes, yes.

Senator PRYOR. You thought you could care for her better than——

Ms. GILBERT. Right, right, with the assistance at home.

Senator PRYOR. And your point, I guess, would be that why do we pay $1,000 a month to a nursing home and nothing to someone like you, or to assist in the caring?

Ms. GILBERT. That is correct.

Senator PRYOR. That's a very good question.

Debra Nelson, let me ask you, your daughter—I think that if I recall this correctly, she testified that her daughter has to take—11-year-old daughter has to take 70, 7-0, 70 pills every day?

Mrs. NELSON. Right.

Senator PRYOR. Tell about how that works and the cost of that.

Mrs. NELSON. OK. She takes antibiotics and then she also has—before she can have anything at all to eat, she has to take 10 pills to digest the food. And sometimes, she has to take Prednisone, which is a steroid, and Tagamet; she takes that four times a day. And the cost in 1986 for her medications alone was $12,000.

Senator PRYOR. Just for the medication?

Mrs. NELSON. Uh-huh.

Senator PRYOR. Have you seen a rise in that particular medication each year?

Mrs. NELSON. Well, it depends on, you know, what medicine she is on at a special time. But what I would like to see done is SSI and TEFRA guidelines to be changed so that they can find her disabled so we'll be able to care more for her at home. Because a lot of the antibiotics that Jennifer used to take when she was younger, she has built up a resistance to and can only take IV drugs now. She can't take oral medicines. And that's where we owe $13,000, for home IV drugs.

Senator PRYOR. Ms. Andrews, you have an interesting concept and that's your—I don't know whether it would be a neighborhood caring facility. Have you proposed this to the State or any of the Federal agencies thus far? Have you made a proposal on this?

Ms. ANDREWS. Not to any State or anything, no, sir. I've put forth an effort to try to get some financial backing for the project, and I went to one person or group and they told me it was too much—it was a foundation that sponsors various worthwhile endeavors. But they said that was too big an undertaking for them to tackle.

So then I went to another person that I felt like had sufficient funds, but their organization only sponsors—I went to them that time just for an individual because I figured I was asking too much for a group. So I—the second person only serves groups. I went to the wrong person for the wrong things. I just get the, well, runaround, more or less. So I don't know to whom I should ask what.

Senator PRYOR. I have that same problem a lot of times. But I'm not being facetious.

Ms. ANDREWS. No, I know, sir. I know exactly what you mean, and I appreciate you knowing what I mean.

Senator PRYOR. Ms. Trickle, I understand that you yourself or your husband has a rather large drug cost per month for your husband; is that correct?

Mrs. TRICKLE. Yes, sir.

Senator PRYOR. Is that increasing or decreasing?

Mrs. TRICKLE. Well, it has increased because last month, the doctor wrote a prescription for him that cost me over $61.

Senator PRYOR. And it had to be filled how often?

Mrs. TRICKLE. It didn't have to be filled. Then they gave him Prednisone, and he takes that every month now. If it wasn't for those drugs that he takes, he would die.

Senator PRYOR. I've got a chart I used in Washington with the drug manufacturers, and it shows that in our country compared to the European countries, that the United States pays more for the same drugs that they pay in Europe that are manufactured by the American drug manufacturers.[6] Here it is, it's going up. That tall green line on the right is what the U.S. citizens pay, and the descending lines are by country. I think we have eight of the European countries there comparing to our prices. We pay the highest price. Those drugs are made in our country. They're made by our manufacturers. We give them a tax break.

By the way, when you see big advertisements in some of the magazines and newspapers, and some of the major drug manufacturers are saying—and they run a series of five of these. They say, "It costs us $125 million to bring out a new drug on the market." You've seen something like that, okay? This is not the fault of your local pharmacist. This is not, the rise of costs of your prescriptions, your local druggist at the corner drug store. This poor fellow or this lady, they're caught in the middle. You've got the Government ratcheting down on the Medicare/Medicaid costs. You have the pharmaceutical manufacturers raising their price. These poor people are making basically the same that they made about 10 or 12 years ago. So don't blame your local druggist, is what I'm about to say.

But your pharmaceutical manufacturer, those top 20, those big guys, they're the ones that I'm after. And they're after me, by the way; I might say that. But those big manufacturers right now say they have $125 million expense.

What they don't tell you is this, under the tax law, they get to write that off for research and development. Then they have another little quirky thing in the tax law that says that they can what they call allocate these taxes over a long period of years so it won't be a big hit.

Then they get the protection of the Food and Drug Administration in Washington, then the U.S. Patent Office gives them a patent that protects them for 17 years. Then once they get all of that, all of their tax write-off, all the patents, all the protection, then what do they do? They move to Puerto Rico to manufacture the drug. Why? Because in Puerto Rico, they don't have to pay any taxes.

In fact, the pharmaceutical's taxes have gone down, not up. And I would say to you, don't fall for that silly line when they say it costs so much to bring a drug out. And the other aspect of that is about 84 percent of the new drugs that are coming out today on the market are what we call "me, too" drugs.[7] They don't serve any purpose except one, to increase the profits of the drug manufacturers. Well, that's the end of that sermon, I got off my subject. We're going to have to conclude this panel, and I wonder if there are any final comments that——

Mrs. TRICKLE. Mr. Pryor, I haven't asked for any help from anyone yet. I didn't know I could get any help. I don't know if I

---

[6] See appendix p. 99.

[7] See appendix, p. 97.

can now or not. But I would like to have enough money to live on just in case I outlive my husband and to pay my medical bills.

Senator PRYOR. That's not asking too much, in my opinion.

Dr. DAVIS. Senator Pryor, in the interest of time, I won't give a sermon, which you will be thankful for. But let me ask a question, of any of you. We appreciate very much your testifying about long-term care, and it needs to be enacted into law; it's going to take time. What you people need is relief now. Do you know of any way, what you're experiencing, getting information about your particular illnesses or taking care of your particular loved one, about getting help to get drugs at less than the going price, to get county and State agencies or voluntary agencies in health care, the heart fund, the pulmonary people, the arthritis groups and all of those? Do you get any help from these people?

Ms. GILBERT. I've requested help from the Area Agency. They told me that unless my mother—she is a diabetic patient also. Unless she took an injection, a nurse had to come in to give her an injection. I could not get the help to come in for 2 hours a day. I can't get any help there.

I've also applied for SSI because if I can get SSI, I can get a card so that we can get our medication. The medication—my medication alone is over $100.

Dr. DAVIS. But you feel that you have access to all the information there is? You are getting all of the entitlements to which you are entitled at the moment? It's not lack of information. You have pursued every effort to get it and it's just not available?

Ms. GILBERT. It's not lack of information; it's just that I can't get it and I need the help.

Dr. DAVIS. Thank you.

Ms. ANDREWS. And I could make do with all of my problems if I had some supplementary funds, like those available from Spinal Cord Commission. I've been a member of that for a long time, but they have only a limited number of funds available for a limited number of people. It's all used up. And as you can understand, it is long-term, so I'm on the bottom rung of the waiting list, and it might take years before I'm eligible for it. I don't believe I've got that much longer to wait.

Senator PRYOR. Let's give these folks a big hand. Thank you very much.

We're going to call our next panel—our next witness, I should say. By the way, they held another Pepper Commission meeting, I think, yesterday, Dr. Davis. I believe it was in Iowa.

Dr. DAVIS. Yes, in Des Moines.

Senator PRYOR. In Des Moines, IA, and I may be going way out on a limb, but I'll bet we've got about five times the crowd they had in Iowa. I don't know because we couldn't get any more. And the State fire marshall, I think, just announced that he wasn't going to allow any more people to come in. So we better be pretty careful.

Ladies and gentlemen, our next witness is Dr. Joyce Berry. Dr. Joyce Berry is the Acting Commissioner, Administration on Aging, U.S. Department of Health and Human Services in Washington, DC. And we're very proud that Dr. Berry is here with us this morning in Arkansas. We would ask you to make your statement, Dr. Berry, and then Dr. Davis and I might have some questions.

STATEMENT OF DR. JOYCE BERRY, ACTING COMMISSIONER, ADMINISTRATION ON AGING, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Dr. Berry. I must say that it is truly a pleasure for me to have been invited to appear here before Senator Pryor and Dr. Davis and the Pepper Commission. I think it's important to just provide some information. I do represent the Department of Health and Human Services at the Federal level. Within the Department of Health and Human Services, there are a number of agencies which have responsibility for addressing some of the concerns that the previous witnesses brought out. I don't think anybody in this room could remain untouched by the stories of the people that we heard.

The Health Care Financing Administration is within the Department of Health and Human Services. That office, agency, is responsible for Medicaid, Medicare, and a host of other programs that impact on older people. The Social Security Administration is within the Department of Health and Human Services. That agency is responsible for Supplemental Security Income, SSI, and a number of other benefits that the older persons and others talked about.

The Administration on Aging, which is the agency that I represent, is the only agency within the Federal Government, to my knowledge, which is responsible for making sure that there is a comprehensive and coordinated system of services, social services, in the community to help older people. The intent of that legislation is that older people can live dignified lives in their later years. I am now deviating, or have deviated, from my official, prepared testimony. As I read it on the plane coming down here last night, it seemed very bureaucratic, but it is the testimony that has been cleared by the Department.

And I do submit that, Senator Pryor, for the record. But I managed last night to prepare some notes of my own for which I will take responsibility.

Senator Pryor. Dr. Berry, tell it like it is, please.

Dr. Berry. I think it's important that we, in Washington, come to the local level to hear some of the real issues that people are facing. I think too often, we, in Washington, are removed from some of the circumstances which should guide us in shaping national policy.

I must say that as a resident of the District of Columbia, although my roots are in Orangeburg, SC, I have a close relationship with the D.C. Office on Aging, which runs a nursing home and which operates a number of other programs in the community for older people. And I visited many times with Veronica Pace, who is the Director of that office, and I've seen firsthand some of the same problems that we've heard here today.

I might also add my own story, that I was a caregiver for my mother, a woman who was over 80 years old when she died 2 years ago. She had raised eight children, and as the youngest of these children, I became the caregiver. And at different points in her elder years, she became very disabled. It was interesting to note that as Associate Commissioner of the Administration on Aging, I had to drive from my job at least 3 to 5 miles just to put eye drops in her eyes after cataract surgery. Why? Because I was unable to find someone who could come in during the day to do that. They told me I needed a skilled nursing person to do that. That's my own story.

But rather than adding to the stories that we've heard here today, as Acting Commissioner, what I'm trying to do is to make our programs relevant. Now, what does the Administration on Aging do? We have State Agencies on Aging across this country. Those State Agencies on Aging are responsible for planning services across the States. There are several State directors here, and I would like to recognize them. Vicki Hunt is from Louisiana. Vicki, would you stand? Esther Wolfe from Kansas. Stephanie Fallcreek is here from New Mexico. And we're missing—there are others here. Edwin Walker, I believe, from Missouri. And any other State directors here, would you please stand? We're very dependent upon those State directors of the State offices on Aging to work with us in trying to meet some of the needs that we heard earlier.

Now, when you get below the State Agency on Aging, you've got the Area Agency on Aging, and I know there are a number of Area Agencies on Aging represented here. Those area agencies have a leadership role within the planning and service area for addressing some of the issues that we heard, as well. Those area agencies—Herb Sanderson, I'm sorry. I forgot to mention Herb, of all things.

Senator Pryor. He's fairly well known around these parts.

Dr. Berry. Herb and I have been friends for a good time. I'll be meeting after this meeting with Herb and the Area Agencies from Arkansas and any other Area Agencies that would like to meet.

Particularly in terms of the topic, though, just let me say in terms of long-term care in rural aging, it's not a strange topic to me. I mentioned my roots in Orangeburg, SC. My father was a farmer. He knew what hard work was and taught me, as well. I was hired by the Department of Agriculture to be a rural elderly specialist some years ago and had responsibility for convening the First National Rural Aging Conference in Iowa. Some of you here were there at that meeting.

What we all know is that services in the rural areas are not as prevalent as they are in the urban areas. And in fact, they are somewhat nonexistent. I wrote an article which Senator Domenici put into the Congressional Record about the silent—the rural elderly, a silent minority. I am not going to go into what the Older Americans Act provides; I'm sure Herb has done that here in the State of Arkansas. But what I do say and what I'd like to say, if I say nothing else, is that the Administration on Aging has a network of State Agencies on Aging, Area Agencies on Aging, and service providers. There are over 670 Area Agencies on Aging across the country. There are service providers. There are over 27,000 service providers throughout the country.

I hope that the Pepper Commission will recognize our network as the Pepper Commission deliberates on issues related to long-term care. I think that our network has a track record of success. I think that rather than creating a separate network to meet the needs of the older persons and others, the disabled, that we ought to use the existing network in place.

I think where there are gaps in our system, which we heard today, we ought to shore up those gaps. And I think the reason I started off describing the Department of Health and Human Services is because some might argue that we're fragmented at the national level. I think the job of the U.S. Commissioner on Aging is to work with the Secretary to make sure that fragmentation does not exist.

I think that the Commissioner on Aging, under the Older Americans Act, has a responsibility for working with HCFA and SSA. Some of the questions raised related to SSI need to be heard by Gwendolyn King. Gwendolyn King is the new Commissioner of the Social Security Administration. And she has said to me personally that she wants to improve the image of that agency with older people. She has a particular interest in outreach for SSI, and the Congress recently appropriated funding for SSI outreach.

HCFA has many policies that impact on older people. I don't think it's appropriate that HCFA provide testimony in terms of Medicaid and Medicare without consulting the Administration on Aging.

All of us work for Secretary Sullivan. And Secretary Sullivan is committed to addressing the needs of older people. He has asked me to form a coordinating council at the Department of Health and Human Services, which I have done, just recently created, where we're going to try—I will make sure that they hear the issues that come out of this meeting. And we will try to make sure that issues fed into the Area Agencies get presented to me and therefore, I can present them to my counterparts.

So I think we can use some help, Senator Pryor in shoring up the gaps that we have in place. The 1987 amendments to the Older American's Act emphasize long-term care. For those of you who don't know, we have a National Rural Center funded. And when that rural center did some investigating to see what the problems were in rural America affecting older people, there were two basic problems: one health, obviously, a concern about the closing of rural hospitals, access to primary care, inadequate supply of doctors, and on and on. I won't go into that. The second one was transportation. We all know, those of us who live in rural areas, that it's difficult getting to the doctor, difficult getting to the stores.

Now, what can be done on the whole? I think it's important to note that as a Federal agency, we know that older persons strongly prefer to receive long-term care services in the community.

I think that the 8-minute film that we saw with Walter Cronkite, and that was the first time I had seen it, clearly depicts what all families fear, which is having to place their relatives in a nursing home. And in light of that, I think we have a serious challenge in terms of being able to provide services in the community. I offer the network of State and Area Agencies and service providers, and that network, with the appropriate resources, as an alternative to placing people in institutions. In fact, we're charged under the act with making sure that older persons stay in their homes and in the communities, and the least restrictive settings for as long as possible. We just need the resources to do it.

We also need case management. I must tell you that I added to my notes after having dinner last night with Herb Sanderson. An older person shouldn't have to guess where to go for help. An older person shouldn't have to go from one agency to another. We're charged under the Older Americans Act with providing case management—older people who need case management; not all older people do, and we need to keep that in mind, as well. Older people are not homogeneous as you all know. A certain percentage of older people need the type of care we are speaking of. Many older people do not. But for those who do need case management, our Area Agencies on Aging are positioned to provide or arrange for the type of case management services that we're talking about, and I'm sure Herb will address that later. What we need—and it's difficult to say, as a bureaucrat, we need to make sure that there are enough case managers and that they are professional and that the quality of care is good.

I'm not going to go on and on, even into the notes that I prepared last night. I just would like to summarize to say that it's important to note that when we talk about long-term care, for years, we've talked about long-term care in terms of institutional settings. If the goal is—and hopefully, when I reach that age, I will want to stay in my home. And I want to make sure that there are services available, even if I am financially able, that the services are there to keep me in my home.

It's important to note, and I hope that the Pepper Commission and obviously the Commission is aware of this, that nonmedical supportive services form the core of the State long-term care programs. Our State Agencies on Aging are struggling to try to find ways to keep older people in their home. Most State officials note that although some limited skilled home nursing care may, at times, be provided, community-based long-term care services usually needed by older persons are nonmedical. And I think long-term care is too often viewed from a medical perspective and the need is for supportive services, as well.

We intend to work closely with you. I want to thank Chris Jennings for urging and insisting that I be present. Oftentimes, the Department shys away from such forums, and certainly Portia, as well. And since being named Acting Commissioner in April, I've met with State directors, Triple A people, service providers. My goal is to get more information.

I meet with Dr. Sullivan every Tuesday morning at 10 o'clock. He has met with the Leadership Council on Aging; he has met with AARP; he has met with the National Association of Area Agencies on Aging. He is committed to being a voice within the President's cabinet to articulate the needs of older people.

Dr. Sullivan opted to have a U.S. Commissioner on Aging. You all may recall, there was a wealth of debate in terms of whether or not there would be a Commissioner on Aging. He made that decision. So I've only attempted to touch on the surface of some of the issues that we have to address, and that concludes my remarks.

Senator PRYOR. Thank you very much, Dr. Berry.

You mentioned Portia and Chris, and I'm really glad you did. Let me introduce the Director of the Committee on Aging in the

Senate. She is a native of Arkansas, a native of Little Rock, Portia Porter Mittelman. Portia, you take a bow, if you will. All right?

And the Deputy Director is Chris Jennings. You've seen him around here a lot this morning. I know Chris is here. I can feel your presence, Chris, but I can't see you. Chris Jennings.

Thank you. We have two other staff members from the Committee. We have Kris Phillips, who is here, and also Fanny Neely, and they are both here representing the Aging Committee staff in Washington.

Dr. Berry, I just have one or two quick questions. We are running far beyond our time that I thought we would be at this point. I am advising our other witnesses that we are going to probably have to call the time on them a little bit. And it was none of our witnesses' fault, these were just poignant stories that needed to get out. But you heard the four ladies who testified. I sat here and listened to those four very courageous women. And somehow or another, I was saying in my mind, I said, these leads—these people are so exhausted and so tired and frustrated at home with the responsibilities that they have, that they don't have time nor the resources nor the energy nor the knowledge to fight the bureaucracy. They don't have that resource left.

I kept saying to myself, Dr. Davis, I said, those people need somebody to fight their battle for them. And I hope that our ombudsmen can do this, and I don't know whether we're equipped to do it. And I think out in rural America, we really are lacking that sort of an ombudsman philosophy, to take a particular case and go head-to-head with the rules and regulations and with the bureaucracies. I wonder if you have any comment on this.

Dr. Berry. Well, we're clearly dependent upon the volunteers who participate in the ombudsman program nationwide. And the Senator is quite accurate in the sense that we need more ombudsmen to go into the nursing homes, to not just investigate the result of complaints there. But also, there's a call to have more ombudsmen in the community who can address some of the particular concerns of the people here. We've got a whole issue related to the board and care facilities, as well.

Many of you are familiar with the situation in California. There's a whole issue related to the representative payee. So the volunteers, however, make up the bulk of the ombudsman program, and each State Agency on Aging has to have an office of long-term care ombudsmen, so we will continue to try to do more there.

[The prepared statement of Dr. Berry follows:]

STATEMENT BY

JOYCE T. BERRY, PH.D.
ACTING COMMISSIONER
ADMINISTRATION ON AGING

Introduction

Mr. Chairman, Members of the Special Committee on Aging and Members of the Pepper Commission, I am very pleased to be here today to share with you some of the efforts and activities of the Administration on Aging in the area of "Delivery of Long Term Care in Rural Areas". We appreciate the opportunity to participate in this extremely important hearing and want to express our interest in continuing to work closely with both the Special Committee on Aging and the Pepper Commission in this extremely important undertaking. I have a very personal commitment and sensitivity to problems of the rural elderly, having served at one point as a Rural Aging Specialist at the Department of Agriculture. In that role, I had the privilege and opportunity of organizing the First National Rural Aging Conference, in 1978, in Des Moines, Iowa. I was also involved in advocating for an increased focus on the rural elderly under the Older Americans Act.

The Administration on Aging was established by the Older Americans Act in 1965 and charged, among other things, with responsibility to serve as the effective and visible advocate for the elderly within the Department of Health and Human Services and with other departments, agencies, and instrumentalities of the Federal Government. Title I of the Older Americans Act, as amended, in its declaration of objectives, clearly addresses the types of long term care the authors envisioned for the older population. It speaks to the need for "full restorative services for those who require institutional care, and a comprehensive array of community-based, long term care services adequate to appropriately sustain older people in their communities and in their homes".

As a part of long term care, the availability of home and community-based care is of critical importance to those older persons who, without benefit of supports in their own communities might otherwise be destined to live out their lives, unnecessarily, in costly institutional settings. It is a well known fact, however, that there are fewer available services in rural areas and that the problems which lack of availability poses are increased because of difficulty in obtaining adequate transportation to those which do exist. Older people in rural areas have special and unique needs. In April of this year, the AoA-funded "National Resource Center on Rural Elderly" at the University of Missouri-Kansas City identified major issues important in the provision of programs and services to the rural elderly in our country. Forty eight States participated in extensive telephone interviews. The two top-ranking issues related to the provision of programs and services to the rural elderly were:

1. Health: concern was expressed from all parts of the country relating to the closing of rural hospitals; access to primary care physicians; inadequate or non-existent supply of doctors; physicians not serving medicaid patients; lack of trained physicians assistants and nurse practitioners; and lack of access to high technology medical services at regional medical centers; and

2. Transportation: universal agreement was shared by all states pertaining to difficulties in financing rural transportation for medical and non-medical purposes. The identification and sharing of transportation resources is a dilemma.

We, in the Administration on Aging, view home and community-based care as essential options within a continuum of long term care, with each type of care designed to help the older person remain as independent as possible, within the environment within which he or she is most familiar and is most comfortable. To this end, the Administration on Aging is working to assist in the development of community-based systems of service throughout the nation which acknowledge the importance and value of both social and health care systems in an overall long term care system for the nation's older population.

Resources of the Administration on Aging assist in building such systems at the Federal, State and local levels. Title III of the Act authorizes the allocation of funds for State and community programs (through Area Agencies on Aging) for purposes of developing comprehensive community-based systems of service and for the arranging for the provision of a variety of supportive and nutrition services. Supportive services include services associated with access to services (transportation, outreach, and information and referral), in-home services (homemaker and home health aides, visiting and telephone reassurance, chore maintenance) and supportive services for families of elderly victims of Alzheimer's disease and related disorders with neurological and organic brain dysfunction and legal services, as well as in-home services for frail older individuals.

At the State level, State Agencies on Aging work with their State counterparts to assure the effective coordination of State level programs toward the building of comprehensive community-based systems of service as does the Administration on Aging, at the Federal level. This multi-level "network on aging" has evolved from a relatively simple program of community service projects for older persons into a complex and highly differentiated "national network on aging" currently consisting of 59 State Agencies, over 670 Area Agencies on Aging and more than 25,000 local nutrition and supportive service providers. These providers are local public, private, or voluntary organizations. Not only does the "network on aging" use Title III monies to provide services, it also is instrumental in leveraging other public and private monies, private foundation contributions and other Federal funds.

At the Federal level, the Administration on Aging has employed a number of strategies in an attempt to increase the availability of effective long term care services nationwide.

We are actively participating in the Rural Health Subgroup of an Interdepartmental Working Group on Rural Development in an attempt to identify ways in which the crisis in rural health care can be resolved. The subgroup is comprised of representatives from the Departments of Veterans Affairs, Education, Agriculture, Transportation, and Health and Human Services.

Through Title IV of the Older Americans Act, we are currently supporting the development of eleven (11) National Aging Resource Centers. Six (6) Centers will pursue issues relating specifically to the development of community-based systems of long term care for older persons. The National Aging Resource Centers on Long Term Care are: Brandeis University, Bigel Institute for Health Policy, Waltham, MA; National Center for Senior Living, Heartland Center for Aging, South Bend, IN; University of California, Division of Geriatric Medicine, Los Angeles, CA; University of Minnesota, School of Public Health, Minneapolis, MN; University of South Florida, Suncoast Gerontology Center, Tampa, FL and National Association of State Units on Aging, Washington, DC. In addition, AoA has funded the National Association of State Units on Aging to establish the National Long Term Care Ombudsman Resource Center.

The new National Resource Center on Rural Elderly, mentioned earlier, is focusing specifically on better means of serving the rural elderly. Also relevant are the AoA-funded National Resource Center on Health Promotion and Wellness, the National Aging Resource Center on Elder Abuse and the National Aging Resource Center on Minority Aging. For several years now, AoA has devoted substantive discretionary resources to an initiative for prevention of illness through health promotion activities. In addition, a cluster of discretionary grant projects have been awarded by AoA to demonstrate effective means of forging linkages between the aging network and the Community Mental Health Centers network to increase the availability of mental health service for the elderly through Community Mental Health Centers.

We have also worked cooperatively with the Health Resources and Services Administration of the Department of Health and Human Services to improve the ability of States and communities in the development of health care systems serving older people and to collaborate with the private sector to improve health care for older persons. In addition, to help assure high quality of in-home supportive services for older persons, the Administration on Aging awarded $2.7 million to twelve State Units on Aging to develop, during 1988 - 1990, new models of quality assurance systems for in-home supportive services. Some salient elements of these models are: quality measures and standards; intermediate sanctions; consumer empowerment; training; and the use of long term care ombudsmen.

Finally, we have just made an award to the Bureau of Maine's Elderly to support a two-year collaborative effort among the Bureau of Maine's Elderly, five Area Agencies on Aging and other community groups to ensure elderly citizens access to hospital-based health care. It is expected that the project will be used to develop a model for increasing access to hospital care in rural areas.

Conclusion

In summary, the Administration on Aging is keenly aware of the need for effective systems of long term care for the nation's elderly and particularly for those elderly who reside in rural areas. I have only attempted here to touch on the surface of some of the things we are doing, but I especially wanted to be here today to learn from your participants -- to listen and hear what special needs we may be overlooking. I eagerly await the testimony of your panelists and I look forward to reading any additional written testimony which may be submitted.

Mr. Chairman, this concludes my prepared remarks. I will be happy to respond to any questions which you and the other members of the Committee and the Commission may have.

Thank you.

Senator **Pryor**. Thank you, Dr. Berry. Dr. Davis.

Dr. **Davis**. Dr. Berry, I just want to commend you on a very fine presentation and to say what I think this audience realizes, that you are truly dedicated to doing something about these problems, and we are very grateful to you for that.

Let me say that the physicians of this country share your good feelings about Dr. Louis Sullivan as Secretary of Health and Human Services. We also are convinced that he's genuinely interested, concerned, dedicated to doing something about these problems, and I'm delighted to hear that you are working that closely with him. Thank you for being here.

Dr. **Berry**. Thank you.

Senator **Pryor**. Dr. Berry, thank you very, very much. We appreciate it. I'm going to switch our next panel around just a little bit, and I hope our other panelists will—I'm going to ask right now that Senator Mike Kinard, and I'm putting a new witness into the mix here, Representative Bill Foster. I'm asking Senator Kinard and Representative Foster if they would come and make their presentation at this point.

Mike Kinard, by the way, is from Magnolia, Senator Kinard. He has been very active, and I must say very, very vociferous in his challenge against some of the elderly care in our State.

And Representative Bill Foster, who I actually served in the State legislature with a few years back, he is probably the most important—the most popular member—I'll say that in public, Bill, and I believe it, of the State legislature. He never even has an opponent anymore. And he is Chairman of the House Committee on Aging in the State of Arkansas Legislature. Thank you, Bill. We appreciate both of you. We understand that both of you have short statements, and we would appreciate your comments. Thank you.

STATEMENT OF REPRESENTATIVE BILL FOSTER, CHAIRMAN OF THE HOUSE COMMITTEE ON AGING, STATE OF ARKANSAS LEGISLATURE

Mr. **Foster**. Thank you, Senator Pryor, out-of-State guests, Dr. Davis and members of the panel, I am Chairman of the Aging and Legislative Affairs Committee. I represent the House. Senator Kinard represents the Senate on that Committee. Senator Pryor is right; I did serve with him, our first term in 1961. I've been in a rut ever since and stayed in the legislature, but I knew that Senator Pryor would go further than the Arkansas State Legislature. Therefore, I have worked closely with him when he was Congressman, when he was Governor, and now the Senator from Arkansas. Not only is he a good Senator, but he has made Arkansas a great State.

Senator **Pryor**. Thank you. Thank you.

Mr. **Foster**. When I call Senator Pryor and Senator Bumpers to help the people of the State of Arkansas, they are always willing and they are good listeners, and we appreciate both of you, Senator Pryor. I'd like to introduce some members of our committee who are here today, and we're interested in what you're doing and we're interested in the people who have come from all over the State of Arkansas. And I want you to know that the Aging and

Legislative Affairs Committee will be at your service at any time that you would want us to help.

We have the Silver-Haired Legislative Day, one of the few States in the United States to have a program like this. They meet once every 2 years. They recommend to the legislature, to our committee, bills that they think might help them, the elderly of the State of Arkansas. Many of those bills are enacted into law and are helping the people that we represent today. I'd like to introduce Mr. John Dawson from Ouachita County. He's on our committee; Mr. Troy Horn from Little River. He represents Little River and Miller County; Dr. Townsend, who represents Pulaski County; Representative Bobby Wood from Craighead County; and Representative Henry Wilkins from Jefferson County.

I also see in the audience representative Lonnie Clark, who represents northwest Arkansas, who is not on our committee, but is interested in your problems.

I want you to know our committee will continue to work to help the elderly, the handicapped, the retired, mentally ill, and needy of the State of Arkansas. Arkansas is a big State with only 2,300,000 people to fund our State agencies. On the State level, we appropriate $1 billion—that's billion, not million, $1 billion a year for human services. I know that this helps a lot. I also know that this is not enough. I also know that we should do more on the Federal level as well as on the State level. And maybe in the future years, we can help the people of Arkansas more than we have in the past. I appreciate you inviting me, Senator Pryor, and continue to do a good job for the State of Arkansas.

Senator PRYOR. Thank you. Thank you very much.

Senator Kinard.

STATEMENT OF SENATOR MIKE KINARD, MEMBER, ARKANSAS STATE AGING AND LEGISLATIVE AFFAIRS COMMITTEE, MAGNOLIA, AR

Mr. KINARD. Thank you, Senator Pryor. And again, as Representative Foster stated, I appreciate the opportunity to have input from the committees that deal with aging.

Senator, on October 19, 1989, as Chairman of the Quality of Care Task Force of the Joint Interim Committee of Public Health, Welfare and Labor, I presented certain concerns of mine relating to the delivery of services to the elderly to a congressional committee. These concerns were about folks primarily in nursing homes as long-term care inpatients under the Medicaid system as presently operating as a Federal/State partnership.

If it appears that this presentation is somewhat duplicative of the former, it's intentional. I've heard nothing from my earlier plaintive cry to that committee, and I'm certain from my recent dealings with the system that it's time to renew some concerns that I've had. Let me say that I'm not a health care professional, and so my approaches may not fit comfortably within the system, which has been devised for delivery of human services and by the human service policymakers.

I do believe, however, that the approaches that I am asking you to consider are within the keeping of the concerns and intent of

Congress as spelled out in the Older Americans Act and then the Omnibus Budget Reconciliation Acts of 1985 and 1987.

While I'm compelled to relate some true-life experiences and some real-world situations to you relating to Uncle Ben and Aunt Lucy out there in the real world, I recognize that you, Senator Pryor, are probably the most inquisitive of all Members of Congress when it comes to down-home fact finding and therefore, wouldn't only listen to an endless string of personal anecdotes and information, but you could yourself give many true life stories that would draw attention to these issues.

Unfortunately, as in most governmental forums, we're limited by time, and I think that we all know that we have many, many, many instances that could be related. But still, all of them identify specific problems with the system.

I see the health care system in the country, Senator Pryor, especially as it serves or doesn't serve the rural elderly in a condition of serious disarray and burdened with fractionalization, fragmentation, being encouraged by the policies of the Health Care Financing Administration. I don't believe this was or is the intention of Congress.

First, the Medicaid system can't function without two things—money and guidelines. The money problems vary from State to State, and they always will in a cost-sharing system. But the guidelines are often too confusing or, in some cases, entirely missing when our Human Services staff workers and even the Governor and the General Assembly try to anticipate and solve problems before they become emergencies.

Second, we all know money drives the system, the system of health care for the elderly particularly. The privatization theory has caught on, and I see it being around for a long, long time as an economic necessity.

Government just cannot deliver the same service as efficiently as can private enterprise. But without strong guidelines and administration in areas such as quality control, distribution of services, and prevention and punishment of wrongdoing, what have we bought for that economic tradeoff? I fear we presently are being forced to buy a system too dedicated to institutionalization, too disjointed to really accomplish the goal of providing quality care in the least restrictive environment, and too out of touch with reality to give Uncle Ben and Aunt Lucy real choices.

This is especially true in rural America, and I think most of Arkansas is rural America. Federal dollars are driving that system and that system presently encourages institutionalization.

I have some suggestions which I feel others appearing here may also have made. If I duplicate those others, then to me, it suggests that that wheel should be considered as the one squeaking. If I suggest something which has already been remedied or is in the process of remediation, then I invite someone to bring me up-to-date. If I offer too simple a solution for a complex problem that the bureaucracy won't consider it, then I beg that you in Congress check with Uncle Ben and Aunt Lucy one more time before you give it up.

One, Congress should direct the Department of Health and Human Services to create a continuum of services which considers all aspects of health care needs to encourge maintenance of individuals in the least restrictive environment. Congress must direct this. It's not going to be done in the present system without that direction.

Two, Congress should adopt a national policy mandating that all health services work together and with other levels of care to form a system for delivery of home health care which has equal status with our system of institutional care. We presently encourage institutionalization rather than offering options to the aging, the ill, and the infirm.

Three, Congress must retain control over its legislation and the implementation process of its laws by assuring that regulations are promulgated in clear and concise language and delivered to the States within specified time frames. Too much time, energy, and money are being wasted by State governments forced to guess about anticipated regulations. Congress should also make sure that agency staff members writing regulations and guidelines for health care providers have a background in case work in the area in which they are writing.

In other words, don't let someone write a manual for delivery of care if he or she hasn't been there.

Four, Congress should address and commit funding to a program dealing with the chronically mentally ill who are over 21 and under 65. Today, a person 40 years old just can't become mentally ill because it's likely he or she won't fit into any Government program.

Five, Congress should mandate that the Department of Health and Human Services adopt a sliding fee scale for Medicaid eligibility to allow persons who are able to pay part of their health care costs to have access to the same quality of services and care which are available for those under the poverty level.

Six, Congress must do something immediately to help the States comply with the law requiring removal of the mentally ill and mentally retarded from institutions of long-term care by providing funding to maintain individuals in community settings. We're fast approaching a crisis, and no real solutions are being offered by the Federal Gvoernment. The States just cannot, on their own, build a whole new system for handling those diagnosed as mentally ill or mentally retarded when they have to be released from their present nursing home environment or when they are rejected for placement upon assessment. The private sector is too distrustful of Federal and State regulators to address the problem with huge capital outlays, Senator. And it concerns me tremendously that in the State of Arkansas, that one department of this State, the Arkansas Development Finance Authority, could issue $86 million worth of bonds to allow one entrepreneur to buy a health care service system in the name of Beverly Enterprises when we have needs out there for community-built health care for good people who have been taken out of nursing homes, and there may not be any money left for that when we get through spending it to help people make money in profiteering.

Until the rules are stabilized, then private money won't be committed. And this is the most acute emergency we now face, but it's only a part and parcel of the overall problem. And I now conclude that Congress must address the continuity of care so that confusion and anxiety of our aging rural America over the system can be ended, and there is one central place for the old, the ill, and the infirm and their families to go in order to access the network of services we already have available. The aged need a one-stop information number as simple as the 911 system. Thank you very much for allowing me to come down. I always appreciate it, and I always appreciate being this close to you, David.

Senator PRYOR. Thank you. We live 40 miles apart. State Senator Mike Kinard, Representative Bill Foster, thank you both very much. Thank you.

In Congress, we can pass all the laws and set up all the programs. But most of the cases, we will find it is the States that implement those programs and then carry out those regulations and rules. So we have heard from two of our State leaders. We're about to hear from two more.

One is Dr. James Maupin, he is with the Arkansas State Board of Health. And Mr. Herb Sanderson. Herb is here with us this morning. He certainly is no stranger. He is deputy director, Division on Aging and Adult Services. We would like for both of these panelists to come forward, and I would also like to ask another witness to come forward, Dr. Rosalie Kane from the University of Minnesota, Professor of Social Work and Public Health. I am going to ask Dr. Kane if she would join this particular panel.

Dr. Maupin, we are sorry that we could not—let me see. I believe that Dr. Elders was going to testify and at the last minute she could not. We very much appreciate you being here, Dr. Maupin.

Dr. MAUPIN. Thank you very much. I fail to appear with energy with which Dr. Elders presents these things. I'll do my best to do so.

Senator PRYOR. Thank you. I may have to—I would prefer you just summarize your statements, if you could, and then we might have some questions.

STATEMENT OF DR. JAMES MAUPIN, ARKANSAS STATE BOARD OF HEALTH

Dr. MAUPIN. Mr. Chairman, members of the committee and the commission, ladies and gentlemen, I appreciate the opportunity to discuss with you an issue which touches or will soon touch virtually every American; that is, long-term care.

The fact that the Senate Special Committee on Aging and the Pepper Commission are holding a hearing today to gather information is itself a statement about the importance of the issue and about your concern.

Long-term care is more than nursing home care. Long-term care encompasses the range of services needed by a person who is functionally dependent, services needed by a person which may be provided in an institution, a community-based organization, or in the home.

The issue of long-term care crosses age, race, sex, and economic levels. All of us face the dilemma of how to obtain and provide long-term care services. According to the national polls, 80 percent of Americans have, or will within the next 5 years, need long-term care for themselves or a family member, or a very close friend. And the need for long-term care is growing dramatically. The greatest users of long-term care are those people over age 85. That population is now projected to grow 234 percent between 1980 and 2000.

The Nation has a three-fold problem. First, there is a very limited availability of some services that we've noted in previous testimony. Second, only those who are poor enough to be eligible for Medicaid can afford the services. Third, the rapidly increasing need and demand for the services may necessarily mean a funding shortage for some other areas.

Except for the very, very poor, there is simply not enough organized system of services for persons who cannot care for themselves. Such services as a bath, a meal, a medication reminder, fresh bed linens, light housework, and a trip to the doctor are often desperately needed by the frail on a routine basis. Such services can mean the difference between living at home and having to go to a nursing home. Without assistance, the only option is often nursing home placement.

The second component of the problem, affordability, is that there is little or no third-party coverage for this. Only if you are very, very poor and medically indigent can you qualify for Medicaid. No other third-party coverage is generally available for long-term care. They are then poverty stricken and thus are medically indigent under Medicaid's definition. Now, Medicaid becomes the payor, even though it was not intended to bear this unnecessarily large portion of responsibility.

Development of a broad array of services for those who are not very, very poor appears to require additional funding. The only existing Federal program which reimburses for long-term care services, Medicaid, may have to provide the Department of Services for the funding of that.

The problems in the area of long-term care can be seen in our daily lives. Multitudes of people are forced into nursing homes before they really need to go to nursing homes. Families and friends give their entire energy and life savings toward long-term care, referring to the ladies that just testified. We only delay this by spending down all of their resources until they are destitute before they are allowed to participate in the Medicaid funding program. Skipping over some of this since we're short of time——

Senator PRYOR. We'll put the full statement in the record, Dr. Maupin.

Dr. MAUPIN: OK, fine. The solution is not a simple one. We need a broad array of services available without regard to age or income. These include nontraditional services. In addition to nursing and personal aide services, transportation to the doctor is important. I have patients every day that can't get to see us; we have to send after them and provide some means of transportation.

Regular housekeeping and laundry for those who can't provide for themselves. Home maintenance can often mean the difference between whether a person's home is safe and livable. Having someone available to provide nutritional assessment and counseling for a special diet may be critical. Caregiver relief should be a key element. We have some families where the family is simply worn out.

They can't get any relief, they can't be put in the hospital, they can't be—get any relief; they just take care of the people.

The development of additional services will probably require additional funding. What do people think about this? I think some of the polls that we've been running shows that most people would vote—65 percent of those polled would be willing to vote for additional taxes if it were earmarked for these services.

I would just like to reiterate in concluding that there are four—these four points I would like to emphasize, that long-term care is one of the Nation's more pressing and growing problems, as we all know. That while we have taken some measures both in the Health Department and elsewhere in Arkansas, the solution to the problem must be broader than what is in place. The Nation desperately needs an organized system to approach the problem. As we reiterated today, we just don't have any organization where you can go to one spot and find out what to do. We need a system which provides persons who are functionally dependent with access to a wider range of services, regardless of income or age. There appears to be sufficient popular support for the type of changes which will be required to deal with the problem.

The statistics which surround us regarding the magnitude of the problem are made up of millions of individual stories. Each one of these stories can be a sad one, as we have seen earlier. I was very moved by the first people that testified today. Or the story could be an uplifting one, a tale of a person who overcomes his own obstacles to remain independent and a part of his family and community, stay at home instead of being institutionalized. Thank you for this opportunity today.

[The prepared statement of Dr. Maupin follows:]

Address to the Joint meeting of the

U.S. Senate Special Committee on Aging
and the
Bi-Partisan Commission on Comprehensive Health Care

by
Dr. James Maupin
Arkansas State Board of Health

---

r. Chairman, members of the Committee and the Commission, Ladies nd Gentlemen: I appreciate the opportunity to discuss with you an ssue which touches or will soon touch virtually every American itizen: Long Term Care.

he fact that the Senate Special Committee on Aging and the Pepper ommission are holding hearings here today to gather information is itself a statement about the importance of the issue, and about your oncern.

Long term care is more than nursing home care. Long term care encompasses the range of services needed by a person who is functionally dependent, services which may be provided in an institution, a community-based organization, or in the home.

The issue of long term care crosses age, race, and sex, and economic levels. All of us face the dilemma of how to obtain and provide long term care services. According to national polls, 80% of Americans have, or will, within the next five years, need long term care for either themselves, a family member, or a very close friend. And, the need for long term carre is growing dramatically. The greatest users of long term care are those over age 85. That population is projected to grow 234% between 1980 and 2000.

THE PROBLEM

The nation has a three-fold problem: First, there is a very limited availability of some services. Second, only those who are poor enough to be eligible for Medicaid can afford the services. Third, the rapidly increasing need and demand for the services may necessarily mean a funding shortage for those services.

First, except for the very, very poor, there simply is not an organized system of services for persons who cannot care for themselves. Such services as a bath, a meal, a medication reminder, fresh bed linens, light housework, and a trip to the doctor, are often desperately needed by the frail on a routine basis. Such services can mean the difference between being able to live at home, and having to be institutionalized. Without assistance, the only option is often nursing home placement.

The second component of the problem, affordability, is that there is little or no third party coverage for these services that are so essential to those persons who cannot care for themselves. The only exception is Medicaid.

Only if you are very, very poor (and thus medically indigent), can you qualify for Medicaid coverage for these services. Since no other third party coverage is generally available for long term care, persons who are not initially Medicaid-eligible must bear the cost from their own resources. Their long term care expenses very quickly drain away all of their resources. They are then poverty stricken, and thus are "medically indigent" under Medicaid's definition. Now, Medicaid becomes the payor, even though it was not intended to bear this unnecessarily large portion of the long term care burden. And the patient is poverty-stricken.

Thirdly, the development of a broad array of services for those who are not very, very poor appears to require additional funding. The only existing Federal program which reimburses for long term care services, Medicaid, must also provide other services.

Medicaid is faced with skyrocketing demands for long term care services, to the extent that those demands limit Medicaid's ability to provide other acute and preventive services. Over a third of the total Medicaid budget in Arkansas is dedicated to Nursing Home care alone. Although most people agree that preventive services for children can be very cost effective, many more such services could be provided if the long term care burden in Medicaid were lessened.

The problems in the area of long term care can be seen in our daily lives:

-- multitudes of people are forced into nursing homes before they really need to be there

-- families and friends give their entire energy and life savings toward long term care, often only delaying the inevitable: poverty and institutionalization

-- existing federal funding for long term care is competing with funding for preventive health services for children

HOW DID WE GET HERE?

Perhaps one of the reasons why we have a long term care dilemma is that, until now, we have necessarily focused our attention upon developing acute and episodic health care services. This has meant that third party payors (Medicare, Veteran's Administration, and private insurors) generally cover needed acute services such as hospital, physician, laboratory, ambulance, physical therapy, short-term home nursing, and other health services. Third party coverage for long term care services is generally not available.

Without the existence of an organized reimbursement system for long term care, service development has been, and may continue to be, slow. Many critical services are simply not readily available to the average citizen.

THE SOLUTION:

The solution is not a simple one. The nation needs a broad array of services available without regard to age or income.

The variety of services must include non-traditional services. In addition to nursing and personal aide services, transportation to the doctor is important. Regular housekeeping and laundry is critical to those who cannot provide that for themselves. Home maintenance can often mean the difference in whether or not a person's home is safe and livable. Having someone available to provide nutritional assessment and counseling for a special diet may be critical. Caregiver relief should be a key element, to enable family members to continue to provide the bulk of care for their loved ones.

Here in Arkansas, we have taken some steps through the Health Department to offer to persons some of the above key services of long term care at home. We offer personal care services and nursing assessment/teaching to all chronically ill and frail, not just those who are poor. We charge people based on their ability to pay. We provide assistance with personal care, meal preparation, and limited housekeeping, under supervision of a registered nurse. On any given day last week, over 700 patients who were chronically ill and frail to the point that they could not care for themselves, but who were not elegible for Medicaid long term care, were served through our program.

But this, while definitely a major improvement for Arkansas, is not the solution. The total array of services is what is needed.

Let's face it: the development of additional services will probably require additional funding. What do people think about the nation's obligating added funding to long term care? Polls have shown that finding a solution to this problem should receive priority over any other national goal. Secondly, 65% of those polled were willing to pay additional taxes if those taxes were directed specifically toward long term care. Public support appears very strong in support of major changes to deal with the issue, even recognizing that such a change may well cost.

Mr. Chairman and members of the Committee and of the Commission, I want to conclude by reiterating four key points:

1. That the long term care dilemma is one of the nation's more pressing and growing proglems;
2. That while we have taken some measures both in the Health Department and elsewhere in Arkansas, the solution to the problem must be broader than what is in place;
3. That the nation desperately needs an organized system to approach the problem. We need a system which will provide persons who are functionally-dependent with access to a wider range of services, regardless of income or age.
4. That there appears to be sufficient popular support for the type of changes which will be required to deal with the problem.

I know that you, too, are concerned, or you wouldn't have taken your time to be here today.

The statistics which surround us regarding the magnitude of the problem are made up of millions of individual stories. Each one of these stories can be a sad one, one which portrays the loss of individual freedom and dignity of a human being. Or, the story could be an uplifting one, a tale of a person who overcomes his own obstacles, to remain independent and a part of his family and community.

Thank you again for this opportunity.

Senator PRYOR. Thank you, Dr. Maupin. Herb Sanderson. Herb.

STATEMENT OF HERB SANDERSON, DEPUTY DIRECTOR, ARKANSAS DEPARTMENT OF HUMAN SERVICES, DIVISION OF AGING AND ADULT SERVICES

Mr. SANDERSON. Thank you, Senator Pryor. It's really a pleasure to be here. Thank you for the opportunity. I won't read all of my testimony; I have given a written copy and I would like for that to be submitted. I would like to say, Senator Pryor, we in Arkansas appreciate your outstanding leadership in the field of aging. It makes me feel more comfortable that this problem is going to be solved.

As we study the issue of long-term care, I hope your colleagues will act on Senate bill 785, the Medicaid Home and Community Care Options Act of 1989 that you are co-sponsoring. I think that is definitely a step in the right direction and we appreciate your support on that.

This country clearly lacks a long-term care system. There are bits and pieces, there are success stories, there are components of a system in place that we can learn from and be guided by, but the current, quote, "system" is fragmented, cruel, demeaning, and woefully inadequate.

The National Governor's Association, the American Public Welfare Association, the National Association of State Budget Officers, the National Association of State Units on Aging, and other organizations have all developed policies on long-term care. They are all very similar in concept. They recognize there is a role for the private sector, but the Federal Government must play the lead in financing. They recommend community care first and institutional care as a last resort. They recognize that States have a responsibility to play a role in administering and coordinating a system, and they recognize that long-term care is not solely for the elderly, but for people of all ages. We know what the system should look like. We easily have the capacity to implement the system. The problem is, how are we going to pay for it.

Well, I hope the Commission will be bold in its thinking and recommend a well-financed, comprehensive long-term care system. I fear, because of deficit concerns, we are years away from such a system.

Therefore, today, I urge the Commission to consider an incremental step. I urge the Commission to recommend establishing a component of the long-term care system that can be put in place at a modest cost; a component that will benefit millions of Americans; a component that will ease and facilitate any future expansions or development in the long-term care system. I urge the Commission to recommend the immediate adoption of a national case management system.

We've heard several problems concerning the trouble with people getting services, and this would help them. Case management, in the simplest terms, helps someone figure out what services are available and helps them secure these services. What does this mean? Well, we heard some stories today; I would like to relate just a few more. There are actual cases here from Arkansas.

A 60-year-old Arkansan was living independently until she had to go to the hospital. Because of the condition of her home, just as much as her medical condition, it was feared that she would have to go to a nursing home. Her house was almost unlivable. There was garbage stacked up; the plumbing did not work; there were holes in the floor. The case manager arranged for volunteers to come in and repair the house and make it livable. She also arranged for an aide to come in and provide assistance daily. Because of this and the work of the caseworker, this person is living today in their own home, not in an institution.

Another gentleman I remember well when I was working in an Area Agency on Aging. It was during the winter. They said this person was going to have to go to a nursing home; he had not paid his utility bills for months. They were going to be cut off; he was going to freeze to death. We sent a caseworker out there. We found four uncashed Social Security checks in his house. With the help of a payee, this person was able to live independently in his own home.

Another lady was living independently—on an income of $326 a month—until she had to have both legs amputated. She applied for both SSI and Medicaid but was rejected. As is often the case, the caseworker found it was not that the client was ineligible for SSI or Medicaid, but that she did not know how to properly complete the application with all the proper information. Today, because of the caseworker, this person is receiving Medicaid and SSI, and has the assistance of a home-care aide.

The problem this Arkansan had in obtaining public benefits is all too common. Obtaining the benefits one is entitled to by law is not easy. On the contrary, it can be a time-consuming, complex, and demeaning journey. Congress has recently provided some money for outreach for SSI, but perhaps we should look no further than the application process, or even no further than the application forms to find out why people don't receive benefits they're entitled to.

I have three documents here with me today, Senator Pryor. One is an application for food stamps. It's 10 pages. On the second page of the application, there are 38 questions. This is an application for SSI benefits. It is 15 pages long. I quit counting the questions at 100. This is an application for $100,000 home mortgage. It's three pages long.

According to analysis by a colleague of mine, the SSI application is written on an 11th grade reading and comprehension level. According to "Aging America," published by the Senate Committee on Aging, over 40 percent of older Americans, 75 years of age or older, have an educational level of less than 9 years.

A 1988 study of AFDC and Medicaid application denials found that only 21 percent were rejected because of excess income. On the other hand, 60 percent of the denials resulted from a, quote, "failure to comply with procedural requirements."

William Crawford, a county social service officer and also a member of the faculty at the University of North Carolina has studied this problem to find out why there is such administrative overkill in the program. What he found was that since 1980, there has been tremendous pressure on the State governments to reduce their error rates on public benefit programs. As a result, in 1988, 49 States owed $1.2 billion in penalties for AFDC; $138 billion in Medicaid sanctions, and $517 million in food stamp sanctions. These are sanctions taken by the Federal Government against the States because they make errors in receiving and processing food stamp applications. Therefore, the States have found it safer to deny applications than to approve them, and this is why we have this administrative overkill.

Our public benefit workers do not like having people fill out 10- and 15-page applications, but we are forced to do so or pay back millions of dollars, if we make a mistake, to the Federal Government. If nothing else, case managers are needed to help older Americans overcome these barriers. The case managers can also help save money. A function of case management is to determine what families can do for their relatives, preserving the formal tax paid services for those who truly need them. And as your chart shows, many times, family members can and do provide needed services. We don't do enough to help families. We could do more if we gave them just a little information, education, and encouragement, and case management could help do this.

If you are frail, sick, or homebound or illiterate, it can be a nightmare to try to navigate your way through the system. Where do you turn for help? In Arkansas, we simply don't have enough organizations.

Therefore, case management is particularly important to a rural State. Arkansas has 75 counties, 486 incorporated towns spread over 53,000 miles. However, we only have 36 United Ways and 17 units of the Salvation Army, all located in the major cities. Where are rural Arkansans to go for help?

Senator Pryor, thanks to your effort when you were Governor of this State, we have a State-funded case management system in place today. We can help some people, but we cannot help everybody that needs the service. Just like we need Federal participation for highways and water work projects, we need Federal participation in a State-administered case management program. I propose specifically that the Older Americans Act be expanded to include this. I think there are four reasons. One, we already have a network, as Dr. Berry referenced. We have State and area agencies all over the United States. They have a mission to advocate for services on behalf of older people. They cover the entire United States and its possessions, and many of these agencies already have a proven track record.

Are all State and area agencies ready to do this? No. Not today. However, I argue it would be cheaper to bring those up to speed that are not than it would be to create a whole new system.

The cost of implementing a system is modest when compared to other components of the long-term care system. Under the Older Americans Act, if we were to increase the funding by 50 percent and couple that with what the States are already doing, we could have a first class case management system in Arkansas. Senator Pryor, that would be about the cost of one, maybe two at the most, Stealth Bombers.

This would be a simple, cost effective system to put in place. Since we live in an information society, a case management system would be an excellent mechanism to get information into the hands of those people who need it the most. It would maximize family support and help guide individuals through the maze of options that are currently available and lay the foundation for a long-term care system we so desperately need. Thank you.

[The prepared statement of Mr. Sanderson follows:]

TESTIMONY BEFORE THE
SENATE SPECIAL COMMITTEE ON AGING
and the
UNITED STATES BI-PARTISAN COMMISSION
ON COMPREHENSIVE HEALTH CARE

by:

Herb A. Sanderson
Arkansas Department of Human Services
Deputy Director for the
Division of Aging and Adult Services

Thank you for the opportunity to appear before the Pepper Commission and express my views. Senator Pryor, your outstanding leadership in the field of aging is very much appreciated in Arkansas. Words alone cannot express our admiration for the job you are doing; not only for older Arkansans but all older Americans.

As we study the issue of long-term care, I hope your colleagues in Congress will pass Senate Bill 785, the Medicaid Home and Community Care Options Act of 1989, of which you are a co-sponsor. This bill, emphasizing home and community care, is definitely a step in the right direction.

This country lacks a long-term care system. There are bits and pieces, there are success stories, there are components of a system in place that we can learn from and be guided by, but the current "system" is fragmented, cruel, demeaning, and woefully inadequate.

The National Governor's Association (NGA), the American Public Welfare Association (APWA), the National Association of State Budget Officers (NASBO), the National Association of State Units on Aging (NASUA), and other organizations have all developed policies on long-term care. They are all remarkably similar in concept. They all recommend community care first and institutionalization as a last resort. They all recognize there is a role for the private sector, but that the federal government must play the lead in financing. They also recognize states have a responsibility to play a role in administering and coordinating a long-term care system. They recognize long-term care is not solely for the elderly, but for all ages. Both the APWA and the NGA policy statements strongly emphasize the need for a case management system. We know what the system should look like. We easily have the capacity to implement the system. The kicker is how to pay for it.

While I hope the Commission will be bold in its thinking and recommend a well-financed long-term care system that meets the needs of our citizens, I fear we are years away from implementation of such a system.

Today, I urge the Commission to consider an incremental step. I urge the Commission to recommend establishing a component of the long-term care system that can be put in place at a modest cost. A component that will benefit millions of Americans; a component that will ease and facilitate any future expansions or developments in the long-term care system. I urge the Commission to recommend the immediate adoption of a national case management system.

Case management, or care management, is designed to effectively and efficiently guide the use of limited public and private resources for the support of an individual. General aspects of case management include developing cost-effective individual care plans, authorizing needed services, and follow-up to ensure that needed services are actually provided. Simply put, a case manager helps figure out what services are needed and helps secure these services.

What does that mean in human terms? A 60-year-old Arkansan was living independently until she had to go to the hospital. Because of the condition of her house, just as much as her medical condition, it appeared she would be unable to return to her home. Her house was basically uninhabitable; there were holes in the floor, garbage was stacked up in every room, and the plumbing did not work. The case manager arranged for volunteers to come in and clean the house, repair the plumbing, haul off the garbage, and fix the floor. The case worker arranged for home-delivered meals, an aide to assist the person in her home, and a payee to manage the individual's finances. Today she is a new person. She is happy, living at home, not in a nursing home.

Another example is that of a moderately functional 62-year-old man who was being exploited. The caseworker was able to arrange for a low-rent apartment removing him from the situation in which he was being exploited. Transportation to the grocery store was also arranged. The caseworker convinced the individual to attend the senior citizens center. With on-going monitoring from the case manager, this person is no longer exploited and continues to live independently.

A third Arkansan (age 68) was living alone on an income of $326.00 per month. She had to have both legs amputated. She applied for both SSI and Medicaid, but was rejected. As is often the case, the caseworker found it was not that the client was ineligible for SSI or Medicaid, but that she did not know how to properly complete the application with all the required information. Today, because of the caseworker, this person is receiving Medicaid and SSI and has the assistance of a home-care aide enabling her to remain at home.

The problem this Arkansan had in obtaining public benefits is all too common. Obtaining the benefits one is entitled to by law is not easy. On the contrary, it can be a time-consuming, complex, demeaning journey. Congress has recently expressed a concern about older people who are eligible for public benefits, but who do not receive them. Perhaps we should look no further than the application process, or even no further than the application forms, to find out why people don't receive benefits like SSI for which they qualify. I have three documents. One is an application for SSI, one is an application for food stamps, and the third is an application for a home mortgage. The SSI application is 15 pages in length. The food stamp application is 10 pages. The application for a $100,000 home mortgage is three pages.

According to an analysis by a colleague of mine, the SSI application is written on an 11th-grade reading and comprehension level. According to *Aging America*, prepared by Senate Special Committee on Aging, over 40% of older Americans 75 years of age or older have an education level of less than nine years.

A 1988 study of AFDC/Medicaid application denials found 2.6 million people were denied eligibility for AFDC/Medicaid. Only 21% of these denials were because of "excess income." On the other hand, 60% of the denials resulted from a "failure to comply with procedural requirements."

William Crawford, a county social service officer and a faculty member at the University of North Carolina, tells why states have adopted a philosophy of administrative overkill:

> In some states more than 80 percent of all AFDC/Medicaid denials resulted form client failure to comply with procedural requirements. Denials for procedural reasons have increased by 75 percent since 1980. During this same period, states have been under intense federal pressure to reduce their eligibility determination error rates. The impending threat of federal fiscal penalities resulted in ever-increasing pressure on state and local agencies to avoid errors made by staff or applicants. Most states have been unable to meet unrealistically strict federal error rate standards. In 1988 forty-nine states owed almost $1.2 billion in penalties for AFDC, $138.2 million in Medicaid sanctions, and $517.2 million in Food Stamp program sanctions. The National Governors' Association estimates that state error rate sanctions may total as much as $3 billion by 1990. Federal fiscal sanctions have not traditionally applied to cases in which agency errors result in the inappropriate denial of benefits to clients. This federal policy (which changed in 1988 for Foods Stamps) made it safer for states to deny applications because there was no risk of federal penalties for improperly withholding benefits from eligible applicants.
>
> Superfluous paperwork and tedious application processes sap the energy and the spirit of both public welfare workers and the applicants who desperately need the benefits which the safety net programs are supposed to afford them. Application procedures have become punitive and demeaning both in their treatment of the client and the attitudes which this type of management philosophy has instilled in local public welfare officials. Is it any wonder that millions of America's poor failed to benefit from a safety net system which as a matter of national and state policy serves up an application process that demeans the applicant, stifles the compassion and professionalism of welfare workers, and serves to deter the poor from obtaining the modest benefits which they are legally entitled.[1]

---

[1] Crawford, William. "Entangled in the Other Safety Net," *New England Journal of Human Services*, Vol. No. 2, page 20.

If nothing else, case managers are needed to help older Americans overcome these barriers. But, not only can case management help people recover benefits, it can also save money. A function of case management is to determine what families can do for their relatives, reserving the formal tax-paid services for those who truly need them. Many times, family members can provide needed services at no cost to the taxpayer if only given a little information, education, and encouragement.

If you are frail, sick, homebound, or illiterate, it can be a nightmare to try to navigate your way through the system. Where do you turn for help? In Arkansas, we simply do not have an adequate number of organizations available to assist people.

Therefore, case management is particularly important to a rural state. Arkansas has 75 counties and 486 incorporated towns spread over 53,187 square miles. However, Arkansas has only 36 United Way organizations and only 17 units of the Salvation Army, all located in our state's larger cities. Where are rural Arkansans to go for help?

Senator Pryor, thanks to some of your efforts when you were Governor of Arkansas, we have a state-funded case management system. However, we cannot assist all people who need help. Just like we need federal participation for highways and work projects, we need federal participation in a state-administered case management program. I propose that this program be administered through the Older Americans Act and, specifically, the state and area agencies on aging. There are four reasons to do this: 1) The state units on aging and the area agencies on aging are already established; 2) they have a mission to advocate for services on behalf of older people; 3) they cover the entire United States and its possessions, and; 4) many of these agencies are already fulfilling this role and have proven track records.

Are all state units on aging and area agencies on aging capable of doing this? No, not today; however, it would be cheaper to bring those up to speed than it would be to create a whole new system.

The cost of implementing such a system is modest when compared to other components of the long term-care system and to other governmental programs. Under the Older Americans Act, Arkansas receives about 1% of the funding. The total funding for the Older Americans Act is somewhere in the neighborhood of $1 billion. If this act were to be expanded by 50%, with the additional resources going to case management, Arkansas could have a first-rate case management system. The additional funding for a national case management system would be about the cost of one Stealth Bomber.

This would be a simple, cost-effective system to put in place. Since we live in an information society; a case management system would be an excellent mechanism to get information into the hands of those people who need it most. It would maximize family support and help guide individuals through the maze of options that are currently available and lay the foundation for the long term care system we so desperately need.

Senator PRYOR. Thank you, Herb Sanderson. It's been a pleasure to have worked with Herb Sanderson for many, many years, and thank you for your kind remarks. I have asked Dr. Rosalie Kane to join this panel. She has come all the way from the University of Minnesota. She is quite a renowned writer in her own right on geriatrics, gerontology. She, in fact, is the editor in chief of the "Gerontologist", a bimonthly scholarly journal. She was to share this panel, I might say, or subsequent panel with Dr. Catherine Hawes, who had to cancel yesterday at a very late time due to the death of the mother of a very close friend and colleague. Dr. Kane, among advisory capacities, serves on the National Advisory Counsel on Geriatrics and Gerontology for the Veterans' Administration. We welcome you to Arkansas and to this panel, Dr. Kane. Thank you.

STATEMENT OF DR. ROSALIE KANE, PROFESSOR OF SOCIAL WORK AND PUBLIC HEALTH, UNIVERSITY OF MINNESOTA

Dr. KANE. Senator Pryor, thank you very much. I'm honored to be part of this panel. And as you said, I am on the faculty of the University of Minnesota School of Public Health and School of Social Work. I might also add that I direct one of six long-term care resource centers that the Administration on Aging has established as a resource to States as they work at developing the kind of systems of long-term care that Mr. Sanderson has talked about. My comments are based on those experiences and about 20 years—more than I'd like to count—of studying long-term care in the United States and in other countries.

I will make only a few brief points this morning, but will give more lengthy written testimony, if I may, to the staff to be entered into the record. As other speakers have already said this morning, long-term care is a vital issue. It affects the way people with functional impairments, most, but by no means all, of whom are elderly, live and die, how they spend their time, who they're with, and the details of their family life. I like to call long-term care "intimate care," because the services that are involved are so personal, so everyday, and they include help with tasks that we all take for granted until we can no longer perform them.

Simply put, the goals of the kind of long-term care system we should aspire to in this country should be two-fold. First, we should help people identify and correct functional impairments and disabilities that are correctable, which means that there must be an accurate assessment and some reasonable link at appropriate times to medical care. And second, and probably more important, the goal is to provide services to compensate for those functional disabilities so as to permit the disabled person to live as meaningful a life as possible despite the impairments. This requires that service programs be flexible, and that they be keyed to the preference and lifestyles of the users. In the field of gerontology, people talk a lot about the ability to perform activities of daily living, which we call ADL's. Long-term care service compensates for ADL impairments. But we must bear in mind that people don't live to perform their ADL's (that is, to brush their teeth, and bathe, eat, and use the toilet), but they perform their ADL's in order that they can live.

Helping people perform their ADL's is not an end in itself, but a means of offering opportunities to disabled people of all ages.

For decades, we have worried in the United States about whether we can afford to make decent long-term care programs available both in residential settings (like nursing homes) and in the private homes of disabled people. While the richest country in the world has been worrying about whether it can afford to subsidize private resources (and you've heard testimony about how substantial those private expenditures on long-term care are) and to supplement family help, other countries are showing that it is indeed possible. Our own research convinces us that it is imminently feasible to develop desirable long-term care programs that both private citizens can afford and governments can offer. Certain principles can be enunciated for developing these programs that will be both desirable and affordable.

First, both public and private money is now being used for long-term care and must continue to be used for long-term care. No reformers even suggest that Government should write blank checks for long-term care services. It's reasonable that consumers contribute to the cost of the care, and certainly that they pay for services over and above defined minimums. So I think we don't have to anguish over that issue anymore. Rather we must decide how to mix and match public and private money in the best way available. The long-term care bill in nursing homes right now is shared 50–50 between consumers and governments. But I would say it is shared in the worst possible way. Consumers pay for nursing home care until they exhaust their resources, as we've heard today, and officially become indigent, and then governments take over.

We don't usually think of it this way, but the Medicaid Program for nursing home care is actually an entitlement that has a deductible of one's entire assets minus a few thousand dollars, and a coinsurance of one's entire income minus, as I think we heard from Ms. Andrews earlier today about $30 a month. Other countries, as my written testimony details, have found ways to share the costs between private and public resources without exacting such hardship on those who have accumulated some private resources.

The second general point is that Federal and State dollars are both needed for long-term care, but the way they are combined and the way the authority is combined is important. At present, the Federal Government already contributes heavily to the cost of long-term care through the Medicare entitlement, through the Federal match to Medicaid, and through other grant programs, and then States contribute very large proportions of their budget through the Medicaid Program and other programs. We are certainly going to need Federal and State cost sharing. But the administration needs to be at the State or even at sub-State levels to ensure sensitivity to local issues, whereas we need sufficient Federal provisos about eligibility and service coverage to ensure equity. The written testimony details that many States have already gone a long way to creating the structure needed to deliver long-term care effectively and sensibly to local circumstances.

The third general point is that both family care and care from nonfamily caregivers will be needed. Families are already supplying large amounts of long-term care, particularly to people outside nursing homes, but also to those in nursing homes. And all evidence assures us they will continue to do so once services are more widely available, both for purchase and under benefit programs.

Catherine Hawes, who asked me to convey her great regret that she couldn't be here and wants her testimony to be in the record, was going to particularly make that point. She highlights two myths—the myth that families aren't helping enough and the myth that families would disappear if we ever offered a few home-based long-term care benefits. Both are truly myths but both die hard.

There's another myth—that the main problem of long-term care would be solved if only citizens could be encouraged to save for their old age. This is simply not true. The kind of physical labor and supervision of care provided by family can't easily be organized or purchased within our current set of social provisions in most States, and most people simply couldn't save enough to protect themselves from the catastrophic costs. From our own current studies of family caregiving, we have poignant examples about the kind of care family members are providing, and we can illustrate the difficulties and sacrifices that are involved. This is especially true if more than one family member needs care at the same time, when the work is physically difficult, when family caregivers are themselves ill, or when the care goes on for years and years and years. Long-term care is really long-time care as well.

There's also research that shows us that family members continue to assist when paid help is available, and that older people and their families tend to want less than professionals think is needed. And I think we can assume that family help will continue once we offer additional and more benefits to people who are very much in need. And at the same time, however, it would be imprudent to predicate long-term care benefits to any requirements of families or any judgments of family capacity. First not all older people or all disabled people have family who can help. Second, it is inherently inequitable to organize a program that way.

The present self-selection mechanisms to offer some sort of safety valve that allow people who, for whatever reason, cannot provide family care. It allows them to opt out rather than place the elder at risk of inadequate or neglectful care. And families, especially those caring for people with severe Alzheimer's disease, also need the security of knowing that there are residential facilities where they could be confident about the care received by a relative when further family care is no longer even logical.

My fourth point is that care at home and caring residential settings are both needed and neither should be considered an alternative for the other. It's necessary to improve both forms of care. We've heard a lot about the fact that people want to stay in their own homes, and we should respect that. At the same time, not everybody can stay in their own homes, and we have a certain amount of work done to make the place where they stay become a home for them.

And there's a lot of information about what people prefer in residential settings. We know it already. They prefer single rooms. They prefer—if they're cognitively intact, not to be placed in close proximity to people who are cognitively impaired. They prefer not to be tied up. Even people with dementia prefer not to be tied up or, in our more sterile language, in "physical restraints". And we're beginning to learn, too, what people prefer in terms of home care. They prefer courteous care and sensible timing. People really don't want to get up in the middle of the afternoon, and we really must organize a way for those services to be responsive to these basic preferences. Once we do so, we find that people tend not to be real demanding.

Let me turn to a brief discussion of long-term care in Canada. In Canada, the provinces are responsible for long-term care. (That's equivalent to the State here.) The public costs are shared by Federal and provincial levels of government. And citizens of all ages with functional impairments are entitled to both home care and to nursing home care as universal benefits, regardless of their income or their assets.

But that doesn't mean long-term care is free, because the principle of contributions also applies. All nursing home residents continue to pay a fixed and affordable portion of the cost as a sort of rent, and families have remained involved in giving care. The demand for home-based services after 10 years or so has proved reasonable, and consumers have a wide variety of choices. And moreover, as provincial and local public entities become the major purchasers of home care, they also exercise substantial quality control and price control over the market.

I think we should be optimistic that the United States can also invent an effective long-term care system. In fact, the tendency to view long-term care as incredibly complex, highly technical, and almost irresolvable does great damage to our ability to move ahead. Some states have already done a great deal to move toward systems of care, and this despite the patchwork of funding now in use. Those States such as Massachusetts and Pennsylvania that have developed broadly based programs with no income requirements, for their home-based, socially oriented care have found that utilization rates for chronic home care have remained manageable.

At least one State has been incredibly proactive at coordinating care in local levels, namely Oregon. It has been able to literally change the shape of services, to reduce nursing home use, and to stimulate an entirely different set of service provisions, some of which I think would have pleased Mrs. Andrews, because they include small group homes, private foster homes in residential settings, and small apartments that can be used as assisted living centers. And all these programs are funded under the Medicaid waiver program, but a vigorous private market for the services has been stimulated.

And I must also mention that I've always admired what goes on in Arkansas. For years, I've been talking to Herb Sanderson and getting my thoughts about flexible programs from him.

I have just a few points in conclusion. One point is about how we should not do long-term care on a long-term basis, and the other points are about how we should do it. How not to do it is to expand the Medicaid Program to introduce a wide array of home-based services that beneficiaries could acquire from certified home-health agencies. That, I think, would really be the wrong way to bring about change. It would be highly inflationary; it would lack in systems controls; and it would be overly medically oriented.

On the other hand, a good approach is to build on the Medicaid waiver programs that have been a very important vehicle for developing long-term care systems. But their incentives need to be carefully examined. For instance right now, there's a perverse incentive that each waiver specifies the maximum number of people that can be served under the waiver. States are thus prohibited from using the Federal match to serve more people, even when the waiver program is well below its dollar cap. That's really something that can be looked at incrementally right now. And then I do agree with Dr. Berry and with Herb Sanderson, that the older Americans network of programs is potentially a vehicle to organize a system of care that older people will trust and feel confident in.

And the last thing I wanted to say regards rural areas, since that's our focus today. The watchword for long-term care in rural areas has to be flexibility. If long-term care programs are to succeed in rural areas, they must not be hamstrung with rules and regulations that prohibit creative development of services. Often, using independent vendors of homemaking will be more feasible than an agency-based effort, for instance. Unconventional providers, such as restaurants, may deliver meals. Driving services could be organized and funded. Fear of liability should not stand in the way of these developments. States should not attempt to be completely standardized in their program across the State.

Arbitrary rules that require a registered nurse to give an injection or in Commissioner Berry's example in her testimony today, to give eye drops really needs re-examination. It's a curiosity that family members are allowed to do absolutely anything, Senator Pryor, almost surgery, for their disabled family members. But if there's no family member available to do it, then you have to go to higher and higher levels of professional licensure to get things done that current professional personnel truly could be taught. We really do have to look at nurse practice acts, not to compromise quality, but to make sure that we don't have unreasonable restrictions in place. They don't work very well with cities, and they work terribly in rural areas.

In the Canadian provinces that I admire so much, the programs in rural areas often differ markedly from those in the cities. They capitalize on the personnel and strengths that happen to be available, they are flexible and creative. With that kind of approach, long-term care protections are attainable in rural areas, too. I thank you very much.

[The prepared statement of Dr. Kane follows:]

ACCESS TO LONG-TERM CARE: IT CAN BE DONE

WRITTEN TESTIMONY

Submitted by Rosalie A. Kane

University of Minnesota
School of Public Health
Division of Health Services Research and Policy

Senator Pryor, ladies and gentlemen, I am Rosalie Kane a faculty member at the University of Minnesota School of Public Health and School of social work. My comments are based on twenty years studying and consulting to long-term care programs in the United states and other countries.

Long-term care is a vital issue, affecting the way people with functional impairments (most of whom are elderly) live and die, how they spend their time, and the details of their family lives. Long-term care could better be called intimate care, because the functional abilities I am talking about concern basic personal activities such bathing, dressing, help with the toilet, help getting in and out of bed, and eating, and help with ordinary tasks such as cooking, cleaning, shopping, and getting from place to place. These are abilities that we all take for granted until we can no longer perform them.

Simply put, the goals of long-term care should be twofold: (1) to help people correct those functional disabilities that are correctable, and (2) to provide services to compensate for functional disabilities to permit the disabled person to live as meaningful a life as is possible given his or her condition. The former goal requires accurate, comprehensive assessment of problems, and reasonable communication with medical personnel. The latter requires that programs be flexible, and keyed to the preferences and lifestyle of the user. We must remember that people do not live to perform these basic activities of daily living (called ADLs in professional jargon), but rather they perform their ADLs to get on with their lives. Providing the personal assistance is not an end in itself, but a means to offering opportunities to disabled people.

For several decades, we have worried over whether the country can afford to make decent long-term care programs available both in residential settings like nursing homes and in the private homes of disabled people. While the richest country in the world has worried about whether it can afford to subsidize private resources and supplement family help, other countries have shown that it is indeed possible.

Our research convinces us that development of desirable long-term care programs that both private citizens and governments can afford is eminently feasible. Certain principles can be enunciated for developing programs that are both desirable and affordable.

1. Both public and private money is used and must continue to be used for long-term care. No would-be reformer suggests that governments should write blank checks for long-term care services. It is reasonable that consumers contribute to the costs of core services, and certainly reasonable that they pay for services over and above defined minimums. At present the long-term care bill is shared 50%-50% between consumers and governments, but in the worst possible way. Consumers pay for nursing home care until they exhaust their resources and officially become paupers and then governments take over. (The Medicaid program for nursing home care effectively is a universal benefit with a deductible of one's entire assets--minus a few thousand dollars and a coinsurance of one's entire income--minus a monthly income of $25 to $45 depending on the state's "comfort allowance.)"

Other countries have found ways to share the costs between private and public resources without exacting such hardship on those who have accumulated resources. In Canadian provinces, for example, each nursing home resident pays about 1/3 of the daily rate, with the resident's contribution a fixed amount that is keyed to the National Price Index. The rates are set to be affordable to the poorest pensioner (SSI equivalent), who is left a monthly sum about three times greater than the most generous state's Medicaid "comfort allowance." Because people do not exhaust their own resources or assets, they often buy further amenities such as a single room. (The amount of permissible extra charge for a single room is rigorously controlled.) Because residents do not spend down, they can continue their contributions indefinitely. The remainder of the daily rate is set through annual negotiations between the payer (the provincial health department) and the provincial nursing home association.

In Canada, charges are sometimes exacted for the personal care and housekeeping aspects of home care, though the nursing and other medically-oriented home care are considered part of insured health care and are typically free for the users.

When drawing examples from Canada, it is important to that long-term care programs in Canada are built upon a base of universal access to acute care services in hospitals and from physicians. The long-term care services have no age barriers, nor do the acute-care services. Because the only universal coverage for acute-care in the United States is under Medicare, it may be that long-term care programs will at first need to be restricted to Medicare beneficiaries and those eligible for Medicaid programs. It is more desirable, equitable, realistic, and politically palatable for long-term care to be construed as a service for all adults with functional impairments, but the programs are best predicated on a universal acute-care coverage benefit.

The other major distinction between the way public and private money is combined for long-term care in Canada is that the public money provides to floor of services (with some copays) whereas in the United States public money is generally the last dollar. Canadian authorities argue that their way of combining the money offers better public control over quality and price. When virtually all enter services through the publicly subsidized route, providers are prevented from charging "what the market will bear" and vigorously promoting services (not always necessary) to those with means. r

2. Federal and state dollars are both needed for long-term care, but the way they are combined is important. At present the federal government contributes to the cost of long-term care through the Medicare entitlement and through the federal match to Medicaid, and other block grant programs. States contribute large proportions of their budgets through Medicaid and specials state programs.

We certainly will need federal and state costsharing, but administration should be at state or even sub-state levels. We also need sufficient federal provisos about eligibility and service coverage to ensure equity. Again there are models in the Canadian federal system, whereby the provinces receive federal matching moneys and administer health programs, but are prohibited from tampering with eligibility or basic service packages.

Many states have already gone a long way to creating the infrastructure needed to deliver long-term care effectively and sensitively to local circumstances. The Community Options program in Wisconsin is one such example, and Oregon's array of Senior Services Division programs is another. The preadmission screening for nursing home care, which is operational almost everywhere, is an important plank in a rational long-term care system, assuming that some assistance in getting services follows the assessment. Most desirable are preadmission screening programs that cover the entire population applying for nursing home care regardless of Medicaid status (such as in Minnesota) and that cover those seeking home-based services from public programs as well. States in the vanguard of community-based long-term care have learned to piece together fragmented funding, and have developed considerable administrative competence. We would do well to build on that as we develop national long-term care policies.

3. Both family care and care from nonfamily caregivers (agencies or individual providers) will be needed. Families are already supplying large amounts of care, particularly to those outside nursing homes (but also to those in nursing homes) and all evidence suggests that they will continue to

do so once services are more widely available both for purchase and under benefit programs. There is a hard-dying myth that the main problems of long-term care would be solved if only citizens could be encouraged to save for their old age. This is simply not true. The kind of physical labor and supervision of care provided by family cannot easily be organized or purchased within our current set of social provisions, and most people simply could not save enough to protect themselves from catastrophic long-term care expenses.

Poignant examples can be presented from our current study of family caregiving financed by the Vira Heinz Endowment to illustrate the kind of care family members are providing. Our data show the difficulties and sacrifices involved, particularly when more than one family member requires care and attention; when the situations persist for many years; when the work is strenuous; when family caregivers are themselves elderly or infirm; and when they struggle with competing obligations and distances.

Other research shows that family members continue to assist when paid help is available, and that older people and their families tend to want less help than professionals think is needed. Therefore, we can assume that family help will continue even after more extensive benefits have been established.

At the same time, it is prudent not to predicate long-term care benefits to any requirements of family or judgments about family capacity. First not all elderly persons have family who can help. Second, it is inherently inequitable if some family members are forced to provide care and some elderly people forced to accept it from family members when others with no family receives the benefit in their own right. Also the present self-selection mechanism offers a safety valve that allows some people who, for whatever reason, cannot provide family care to opt out rather than place the elder at risk of inadequate or neglectful care. Families--especially those caring for people with severe Alzheimer's disease--also need the security of knowing that there are residential facilities where they could be confident about the care received by a relative when further family care is no longer even logical.

4. <u>Care at home and care in residential settings are both needed. Neither should be considered an alternative for the other.</u> There has been twenty years of demonstration projects and studies in the United States to attempt to show that community care is a cost-effective alternative to nursing home care. For a variety of reasons--some related to research design and some to the populations needing long-term care, the case has not been proven. Long-term care is needed in both institutional and community forms. If only institutional care is available, some people will struggle without services and postpone nursing home admission. It surely is improper to fail to establish necessary services because they do not replace another necessary service.

Furthermore, at some level of need, it will be less expensive to provide care in residential settings than in people's own separated homes. The Medicaid waiver programs in the United States and the long-term care programs in the Canadian provinces all reasonably expect that public expenditures on home care be no more expensive care of the same person would be in a nursing home. Given that economies of scale are necessary, some people will still need to relocate to places where care can be delivered more efficiently.

Setting up a sharp dichotomy between nursing home care and all other services--what I call the "alternatives mentality"--is dysfunctional for several reasons. First, it diverts attention from the need to change the nature of institutional settings so that they are more desirable places to live. Second, it assumes that those in nursing homes are no longer community residents able to avail themselves of community services and opportunities that could be used by disabled people with another address. Third, it neglects the reality that many people use nursing homes for short periods as part of a planned recovery after a hospitalization. And fourth, grouping every community-based service as a bundle that together constitute an "alternative" to nursing homes has distracted us from the important work of determining how to better organize and target the separate components of community care such as home care, day care, respite services, transportation, home-delivered meals, and so on.

5. Care should be provided in forms preferred by those using it. Much is known about what users would prefer in a residential setting. People prefer privacy, and continued independence in dictating their own routines. They want their possessions to be safe. They would like to be able to offer a guest a chair and some hospitality, and indeed would like access to a refrigerator. They prefer not to be tied, or to see people tied down. They like to be treated with dignity and respect. They like staff members who are kind and pleasant. They like to have some control over summoning physicians and to have a chance to talk to their doctors rather than have everything interpreted by nursing home staff. Generally speaking, they prefer settings that do not represent an abrupt break from life as they have known it for 80 years. Also those who are cognitively intact desperately prefer not to be grouped in close proximity with the cognitively impaired.

We are slowly beginning to learn something about preferences for home care as well. People are seeking home-based services that are dependable from providers who are honest, courteous, and kind. Older people are reluctant to have someone "take over" in their homes; they would still like to be able to suggest the day's routines. And, of course, the scheduling of home care needs to be compatible with the client's preferred schedule. Few want to wait until the afternoon for help with getting up, bathed, and dressed.

In Canada, many of the five criteria are met. Provinces are responsible for long-term care programs, but the public costs are shared by federal and provincial levels of government. Citizens of all ages with functional impairments are entitled to both home care and nursing home care as universal benefits regardless of their assets or incomes, but substantial copayments are made by consumers (equalling about 1/3 of the nursing home daily rate), and patients and families are free to subsidize care over and above the minimums provided. If an older person want to pay for a home health aide to clean the silver, this is fine, but she must use her own resources over and above what is furnished by the province because of her functional impairment.

And these programs in Canada seem to have worked. Families have remained involved in giving care; the demand for home-based services is reasonable; and consumers have a wide variety of choices. Moreover, as provincial and local public entities become the major purchasers of home care, they can exercise substantial quality control (and price control) over the market.

We should be optimistic that the United States can also invent an effective long-term care system. In fact, the tendency to view long-term care as an incredibly complex, highly technical, and almost irresolvable problem does great damage to our ability to move ahead. States have already done much to move toward a system of care--and this despite the patchwork of funding streams now in use. Those states that have developed broadly based programs that have no income requirements--for example, Massachusetts, Pennsylvania--have found that utilization rates for home care remain manageable. A state that has been proactive in coordinating care at local levels--namely, Oregon--has been able to change the shape of services, reduce nursing home use, and stimulate a set of service provisions that have been purchased by private payors.

I conclude with two caveats, and a comment about rural services.

(1) Expansion of the Medicare program to introduce a wide array of home-based services that beneficiaries could acquire from certified home-health agencies would be the wrong way to bring about change. It would be highly inflationary and lack system controls.

(2) The Medicaid waiver programs have been an important vehicle for building long-term care systems in our states. Their incentives should be carefully examined, however. It is a perverse incentive that each waiver specifies the maximum number of people that can be served. States are, thus, prohibited from using the federal match to serve more people even when the waiver program is well below its dollar cap.

(3) Finally, regarding rural areas, the watchword is flexibility. If long-term care programs are to succeed in rural areas they must not be hamstrung with rules and regulations that prohibit creative development of services. Often independent vendors of homemaking service will be more feasible than an agency-based effort. Unconventional providers such as restaurants may deliver meals. Driving services could be organized and funded.

Fear of liability should not stand in the way of these developments. States should not attempt to be completely standardized within their boundaries. In the Canadian provinces I so admire, the programs in rural areas often differ markedly from those in the cities, capitalizing on the personnel and strengths that happen to be available. With flexibility and creativity, long-term care protections are attainable in rural areas too.

Senator PRYOR. I want to thank all three of you very, very much for coming here today. Let's give them a nice hand. Thank you.

Our next panel is Dr. Roger Busfield, President of the Arkansas Hospital Association.

Let's all have a 7th inning stretch here. Benno Salewski, who is the Executive Director of the Arkansas Health Care Association, Amber Reed, President-Elect of the Arkansas Home Health Agencies, and Mr. Ernie Yeager from Jasper, of the Arkansas Pharmacists Association.

Our 7th inning stretch is over now. We're going into about the 8th inning actually, so we're going into the final portion of our hearing.

Dr. Roger Busfield is President of the Arkansas Hospital Association, Dr. Busfield.

STATEMENT OF DR. ROGER BUSFIELD, PRESIDENT, ARKANSAS HOSPITAL ASSOCIATION, LITTLE ROCK, AR

Dr. BUSFIELD. Senator Pryor, the Association strongly endorses Senate bill 1466, your bill, the Rural Hospital Improvements Act of 1989. We believe that passage of this bill will contribute to the effort to keep our rural hospitals open and available for the people of our rural areas, and we thank you very much for sponsoring this piece of legislation.

Senator PRYOR. Thank you, sir.

Dr. BUSFIELD. We do urge you that when we get around to funding that act once it passes, that you make it not subject to budget neutrality so that you don't divert funds from other worthy programs to finance it.

The provision of long-term care services to our aging population should be of paramount importance and given absolutely the highest priority by our Congressmen. Perhaps the greatest fear older people have is being separated from their loved ones in a nursing facility in another community some distance from home.

Well, due to the shifting patterns of care today, many of the patients formerly treated as hospital inpatients are now treated as outpatients or in alternate care settings. Many are in home health programs.

Well, some of our rural hospitals here in Arkansas are faced with excess bed capacity, some as high as 60 to 70 percent of their existing beds. And the opportunity for those beds to be used for inpatient care is very, very—it just won't happen. These beds should be converted to long-term care use. Such hospital-nursing care combinations can be operated efficiently and economically without any great outlay of capital funds.

The Special Committee on Aging is urged to take a look at this excess bed capacity in America's rural hospitals and not necessarily for skilled, or for intermediate care that the nursing homes are providing so well, but for other levels such as respite care, boarding care for the elderly without families or homes, and mimimal care for those retirees able to help themselves most of the time.

It was announced recently that the number of us age 100 or more is now in excess of 50,000; that in a very few years, that number is expected to double. We are living longer, and many of us are living better. But there are still many of us who view the golden years as anything but golden. And I believe we, and I mean the we—all of the we, Congress, Arkansas, all of us, have an obligation to do whatever we can to brighten up the dismal years and to make life enjoyable as we can.

We urge you to please take a look at our excess hospital bed capacity, not in terms of traditional use, but in the many innovative ways these beds can be used for our aging population. Thank you.

Senator PRYOR. Thank you, Dr. Busfield. Thank you, very much, Dr. Busfield.

From the Arkansas Health Care Association, now, Benno, help me with your last name. I always have trouble with it.

Mr. SALEWSKI. It's SALEWSKI, Senator.

Senator PRYOR. All right.

Mr. SALEWSKI. If you were Norwegian, you could put "lefts" in the middle of it.

Senator PRYOR. All right. Here we go. Well, we are welcoming you here today and look forward to your statement. Thank you.

STATEMENT OF MR. BENNO SALEWSKI, EXECUTIVE DIRECTOR, ARKANSAS HEALTH CARE ASSOCIATION, LITTLE ROCK, AR

Mr. SALEWSKI. Thank you, Senator. Our organization, the Arkansas Health Care Assocation, every day provides care for some 19,000 chronically ill and elderly persons; therefore, we recognize the importance of this discussion of a critical problem: how to provide long-term care to the elderly and chronically ill in the rural areas of our State.

I have summarized my written comments, which I have submitted to your staff, and I have basically three points to make. The first has not yet been raised. That has to do with the serious and growing shortage of nursing personnel in the nursing facilities around the country. For long-term care providers, the shortage of nursing personnel—that's nurses, LPN's, and nursing aides or nursing assistants—is especially critical because the availability of qualified nursing staff is the key to providing high quality and long-term care.

Most deficiencies found by State and Federal surveyors inspecting nursing facilities relate to the lack of adequately prepared staff. Now, one of the primary reasons for this shortage is the significant differential between salaries for nursing staff and nursing homes and those working in hospitals. RN's in nursing facilities earn an average of 26 percent less as head nurses and 31 percent less as staff nurses than their hospital counterparts. LPN's earn 10 percent less and nursing assistants (and they're the ones who really provide the hands-on care), they earn 33 percent less than those employed in hospitals.

Senator PRYOR. Now, are we talking about basically nursing homes make this much less than the ones employed at the hospital; is this correct?

Mr. SALEWSKI. That is correct. Those are national figures. To move toward a solution for this problem, we advocate several things. First of all, the financing of long-term care should be changed to permit the wages and salaries of nursing personnel to match the prevailing wages in hospitals.

Our association and our national affiliate, the American Health Care Association—I believe you've met them—support legislation introduced by Congressman Walgren, HR 1649, which provides for increased salaries for nursing home staff at costs passed through to the Medicaid Program. We would ask the support of this Senate Special Committee and the Commission.

Second, I believe it important that incentive programs such as loan forgiveness or interest forgiveness programs similar to those suggested for doctors be established to encourage nursing personnel to serve in rural areas.

It is often the case that trained nursing personnel in this State and other States tend to migrate to the larger cities of our stage rather than serving in rural areas.

Third, the Federal funding for training programs in geriatric nursing be expanded, and clinical affiliations between nursing programs and nursing facilities be encouraged and supported so that more nurses choose nursing homes as the first choice for their work setting.

The second point I want to focus on has already been raised by several of the speakers, and that is the lack of coordination of long-term care services in rural areas. The so-called long-term care system is really a nonsystem, a crazy patchwork quilt of programs that are highly uneven regionally and locally spread across several systems, the physical care system, the social service, the mental health system. And many of these programs, as you've heard already this morning, are underfunded and are therefore inadequate to meet the needs they are organized to address. Now, they're doing the best job they can, and this is true despite all of the best efforts of groups like the area agencies on aging and others.

With regard to Roger's comment on swing beds, we understand that rural hospitals need help. However, we insist that any changes or any new programs would be developed with due regard for the impact on existing services and providers. We want to be sure that the rural hospitals are saved without impacting negatively on their neighboring nursing homes and their viability.

To move toward a solution for this problem, we would advocate several things. First of all, as several others have said, we need Federal long-term care policies that will lead to development of a rational, coordinated system of long-term care services available to all rural residents. Dr. Berry's comments are at point here. As we expand services and add new services, we need Federal standards that will ensure that all providers of long-term care services meet high standards of quality, that they provide adequate number of trained staff, maintain safe and sanitary physical plants, protect nursing resident rights, and give adequate attention to resident care needs. We have to be sure that new services maintain the same standards we expect of existing services.

Along with this, we need inspection of all long-term care service providers by trained surveyors and enforcement mechanisms to ensure the quality of service in all community- and home-based programs, waivered services, and program options. The OBRA requirements, for example, should be applied to all of these programs.

More specifically, Senator, we need policies that will ensure fair competition between the various providers of long-term care services. I'm thinking here about, by way of example, the elimination of the differential Medicare routine cost limits, the Section 223 limits. We favor this to ensure that nursing homes and hospitals receive the same reimbursement for the same services.

And finally, a point that was raised by Mrs. Trickle, and it is a concern, I believe, to many of the elderly in our State; that has to do with the skilled nursing benefit of the Medicare Catastrophic Coverage Act. We understand that Members of Congress are under extreme pressure to significantly revise the act or even repeal it. But we urge members of the Commission and the Senate Special Committee to vote to retain the Medicare SNF benefit.

First of all, it's not a new benefit at all, but an expansion of an already existing benefit in the Medicare law. Second, perhaps most important, this benefit has made skilled nursing care available to all of those with legitimate medical needs. Skilled nursing benefits are being provided to many elderly who otherwise would not receive them. Mrs. Trickle testified to this earlier. And third, the catastrophic law, or this part of it, has attracted more skilled nursing facilities to the Medicare Program, making more beds available across the country. Any many of these new Medicare beds, serve rural areas and they are desperately needed there. So we would urge the commission and the committee to vote to retain that SNF benefit. I thank you for the opportunity to share these thoughts with you.

[The prepared statement of Mr. Salewski follows:]

LONG TERM CARE IN RURAL AMERICA:
A FAMILY AND HEALTH POLICY CHALLENGE

Statement by Benno W. Salewski,
Arkansas Health Care Association

The Arkansas Health Care Association is pleased to have the opportunity to testify at this joint field hearing of the U.S. Bipartisan Commission on Comprehensive Health Care and Senate Special Committee on Aging. The Arkansas Health Care Association represents 204 proprietary, non proprietary and publicly owned nursing facilities in Arkansas. Our members provide care for more than 19,000 chronically ill and elderly persons each day. Therefore we recognize the importance of this discussion of a critical and difficult problem; how to provide long term care to the elderly and chronically ill in rural areas of our state.

As members of the Commission and the Special Committee are well aware, the long term care industry is in a period of rapid and significant change. The Omnibus Budget Reconciliation Act of 1987 (OBRA) contained the most comprehensive overhaul of nursing home laws since the enactment of Medicare and Medicaid programs. The Budget Reconciliation now in mark-up will continue the overhaul process, yet none of the existing or proposed OBRA reforms address the special problems of providing long term care in rural America and rural Arkansas.

The demographics of these problems are well known by Commission and Committee members. The greying of our population, the concentration of elderly in rural areas, the closings of small rural hospitals, and shortage of doctors in rural areas have all been well documented and will surely be discussed by other witness at this hearing.

It is clear that to meet the needs of the growing number of rural elderly, our nation's health policy makers must give high priority to putting in place and adequately funding a full spectrum of long term care services in rural America.

Several problems must be overcome before this goal can be achieved. My comments shall focus on three problems of particular concern to long term care providers in Arkansas.

The first problem is a serious and growing shortage of nursing personnel in nursing facilities. The growing nurse shortage is creating serious staffing problems in hospitals and nursing facilities in all geopraphic areas. For long term care providers, the shortage of nursing personnel, RNs, LPNs and nursing assistants (NAs) is particularly critical. The availability of qualified nursing staff is the key to providing high quality long term care. Most deficiencies found by state and federal surveyors inspecting nursing facilities relate to lack of adequately prepared staff. Yet, staffing pressures will only worsen with the implementation of OBRA and revised Conditions of Participation proposed by the Department of Health and Human Services which will require facilities to meet higher nursing staffing levels. Furthermore, the most recent HHS Report on Nursing predicts that in 1990 up to 500,000 nurses will be needed in nursing facilities; by the year 2000, one million will be needed. In the face of this, recruitment of nursing staff has become much more difficult than in the past; many of our member facilities report it takes months to fill RN, LPN and NA vacancies.

Several factors contribute to the nursing personnel problem. Nursing staff, once trained, tend to migrate to the larger cities of our state rather than seeking employment in rural facilities.

Of more importance is the significant differential between salaries for nursing staff in nursing facilities and those working in hospitals. Long term care is predominately publicly financed. Seventy percent (70%) of nursing facility residents in Arkansas are Medicaid recipients. Federally and state imposed rates determine the limits for salaries of long term care nursing staff. These salaries are seriously inadequate, especially for experienced nurses, in view of the other more lucarative options open to them.

Nursing salary data provided by the US Department of Labor indicates that RNs in nursing facilities earn an average of 26%

less as head nurses and 31% less as staff nurses than their hospital counterparts; LPNs earned 10% less and NAs earned 33% less than those employed in hospitals. The explosive growth of alternative health care delivery systems and community based programs makes the competition for already scarce RNS and LPNs even more intense.

Recruiting, training and retaining nurses assistants in rural facilities can be particularly difficult. The wages of many NAs in Arkansas' rural areas are close to the minimum wage. As a result, the opening of a new poultry processing plant in a neighboring community, for example, can lead to a large scale resignation of NA staff. As long as long term care providers are locked into payment rates set in a cost containment environment, they will have difficulty attracting and keeping the most capable nursing staff.

Another contributing factor is the shortage of programs in gerontology and the lack of involvement between schools of nursing and nursing homes. When nursing programs do no provide training in geriatric nursing and and nursing students have no clinical experience in long term care facilities, nursing students will rarely select nursing facilities as their desired practice setting. Historically, nursing facilities have been the practice setting of last resort for nurses. In fact, while there are more nursing homes than hospitals in this country and more nursing home patients than acute hospital patients, only 7.1 percent (7.1%) of all employed RNs work in nursing homes.

To move toward a solution for this problem, we would advocate the following:

1) That financing of long term care be reformed to establish nursing homes rates that permit the wages and salaries of nursing personnel to match prevailing wages in hospitals. Our Association and our national affiliate, the American Health Care Association, support legislation introduced by Congressman Walgren (HR 1649) which provides for increased salaries for nursing home nursing staff with the costs "passed through" to the Medicaid program. Key provisions of the bill include requirements for state

Medicaid programs to pay the cost of increased nurse wages up to the maximum rate of prevailing wages paid to hospital nurses in the same locale, and for nursing homes to return funds paid in anticipation of wage increases but not actually used. We encourage members of the Commission and the Special Committee to support Congressman Walgren's bill. We would also observe that the budget reconciliation process is an opportunity to create payment methodologies that assure equity between hospital nursing salaries and salaries for nursing staff working in nursing facilities.

2) That incentive programs such as loan forgiveness or interest forgiveness, similar to those proposed for doctors, be established to encourage nursing personnel to serve in rural areas.

3) That federal funding for training programs in geriatric nursing be expanded and clinical affiliations between nursing programs and nursing facilities be encouraged and supported.

The second problem of concern to long term care providers is the lack of coordination of long term care services in rural areas. The "long term care system" is in reality a non-system - a patchwork of programs that are highly uneven regionally and spread across the physical care system, the social service system, and mental health system. Many of these programs are underfunded and are inadequate to the need they are organized to address. As a result, many are left without access to services.

In response to this situation programs have been developed or proposed, in piecemeal fashion, to attempt to solve one aspect of the problem, often without apparent regard for the impact on existing services or providers.

An example of this is the hospital swing bed program. This program was enacted to improve the financial status of rural hospitals suffering from low and declining occupancy rates by using their excess capacity to provide skilled nursing care. Although one intent of the program was to provide long term care where there was a pressing need for nursing home beds, the impact of swing beds on nearby nursing facilities has not always been adequately considered; indeed sometimes that impact has been ignored. Many small rural hospitals need help. However, that help should not come at the expense of rural long term care facilities.

In addition to swing beds, a number of new programs, waivers for home and community services and various alternative service initiatives have been enacted or proposed. It is not always clear or apparent that the relationship of new services to already existing long term care services has been considered or evaluated. Our associations are not opposed to the development of a full range of long term care services in rural areas, indeed we urge such development. However, we believe the distinctions between various levels of care should not be blurred to ensure that individuals are appropriately place in the program that can best serve their needs. We also believe that federal standards are necessary to ensure uniform, quality services and resident protections. Further, we believe that decisions on the placement of the frail elderly must be based on the needs of the individual and not on cost containment considerations.

To move toward a solution for this problem we would advocate the following:

1) Enactment of federal long term care policies that will lead to development of a rational, coordinated system of long term care services are available to all rural residents.

2) Federal standards that will insure that <u>all</u> providers of long term care services meet high standards of quality; provide adequate number of trained staff; maintain safe and sanitary physical plants; protect resident rights and give adequate attention to resident care needs.

3) Inspections of <u>all</u> long term care service providers by trained surveyors and enforcement mechanisms to ensure quality of service in all community and home based programs, waivered services and program options.

4) Policies to ensure fair competition between the various providers of long term care services including elimination of the differential in Medicare routine cost limits or "Section 223" limits to ensure that nursing homes and hospitals receive the same reimbursement for the same services.

The third problem of concern to members of the Arkansas Health Care Association has to do with the skilled nursing facility (SNF) benefit of the Medicare Catastrophic Coverage Act. We understand that members of Congress are under intense pressure to significantly revise, delay or repeal the Act. We would urge members of the Commission and Senate Special Committee to vote to retain the Medicare SNF benefit. First, it is not a new benefit, but as expansion of an already existing benefit in the Medicare law. Second, and most important, the SNF benefit has made skilled nursing care available to all those with legitimate medical needs. Skilled nursing benefits are being provided to many elderly who otherwise would not receive them. Third, the Catastrophic Law has attracted more skilled nursing facilities to the Medicare program making more beds available across the country. Many of these beds serve rural areas. For these reasons, this benefit for America's frail elderly should be maintained.

I thank you for the opportunity to share our concerns and insights with you today.

Senator PRYOR. Thank you very much, sir.

Well, we've heard a lot of statements today and a lot of issues revolving around home health care. From the Arkansas Home Health Agencies, we have Amber Reed, the President-Elect, from West Memphis. Amber, we look forward to your statement.

STATEMENT OF MS. AMBER REED, ARKANSAS ASSOCIATION OF HOME HEALTH AGENCIES, WEST MEMPHIS, AR

Ms. REED. Thank you. I will be real brief. Many of the issues that I have and the ideas that I had have already been expressed for the need of more home health services in Arkansas—it's in my report, so I won't go any further with that. I feel that rural health care in Arkansas is in grave danger. Hospitals are failing in areas where unemployment is high and economic conditions are poor. Home health is available at this time all across our State. But with the decrease in our reimbursement rate due to the low wage index, I'm not sure how many will be able to survive.

Our reimbursement rate will be decreased by approximately $4 per skilled nurse visit. The wage index is embarassingly low for Arkansas. We are the lowest of all the States. We are lower than Puerto Rico.

Senator PRYOR. You mean like when you go and provide home health care, that Arkansas is the lowest in the Nation for that fee that's paid to the person? Is that what——

Ms. REED. Yes, yes. This is what I'm talking about, really, is the new wage index that was recently released, and I think you got a copy of it from our executive director. But our surrounding States, Mississippi, Tennessee, Oklahoma, Louisiana, Texas, all registered 0.8 and above. Arkansas registers 0.45. We are in desperate need. We have contacted HCFA, and they tell us the only thing that can be done is through you, and so that's why we——

Senator PRYOR. Through me?

Ms. REED. Yes.

Senator PRYOR. The buck stops here. I was trying to blame someone else with it. Thank you. Are they talking about the Finance Committee and the ——

Ms. REED. Yes, sir. OK. Due to the DRG, the prospective pay system, hospital admissions and stays have decreased tremendously. Patients are discharged quicker and sicker from the hospitals, and we need home health care and more services to be provided in the home so that people like Mrs. Trickle could come home and stay with her, where she could have the services that she needs.

Recent changes in Medicare guidelines will allow a lot more care to be provided under this, but our Medicaid system desperately needs to be looked into. As far as relating to hospitals, I had talked with my local hospital administrator, and one point that she asked me to bring up was that in many metropolitan areas, they state that they have the same percentage of Medicare and Medicaid as rural hospitals. But one factor that is always overlooked is that in metropolitan areas, a lot of times, they have people who are affluent and who could afford to pay co-insurance and deductibles, where in the rural areas, this is rarely the case.

Also, the failing industry in our rural areas causes us to have patients without insurance while larger hospitals use this to offset their costs. We are also very proud to have the coverage of the Medicare Catastrophic Coverage Act dealing with home IV therapy. But as this gentleman next to me said—I won't say his last name either—that much of what is being presented is already covered under Medicare, and we feel that the act needs research into this and find areas that are neglected so that safe and effective treatment can be rendered. As the National Association of Home Care always says, there's no place like home, and I feel that that's the view of the Arkansas Association of Home Care. Thank you.

[The prepared statement of Ms. Reed follows:]

STATEMENT OF AMBER W. REED, RN
WEST MEMPHIS, ARKANSAS

BEFORE THE SENATE
SPECIAL COMMITTEE ON AGING

HEARING CHAIRED BY SENATOR DAVID PRYOR, ARKANSAS

AUGUST 22, 1989

SENATOR PRYOR:

GOOD MORNING, MY NAME IS AMBER REED, I AM ADMINISTRATOR OF ARKANSAS HOME HEALTH IN WEST MEMPHIS. I AM A REGISTERED NURSE AND HAVE BEEN IN THE HEALTH CARE FIELD FOR 17 YEARS. I REPRESENT THE ARKANSAS ASSOCIATION OF HOME HEALTH AGENCIES.

RURAL HEALTH CARE IN ARKANSAS IS IN GRAVE DANGER. HOSPITALS ARE FAILING IN AREAS WHERE UNEMPLOYMENT IS HIGH AND ECONOMIC CONDITIONS ARE POOR. WHAT WILL OUR RURAL COMMUNITIES DO FOR HEALTH CARE? HOME HEALTH IS AVAILABLE IN ALL AREAS ACROSS OUR STATE. BUT WITH CUTS IN OUR REIMBURSEMENT RATES, I WONDER HOW MANY WILL SURVIVE.

WHEN I STARTED PREPARING FOR THIS TESTIMONY, I COULD NOT DECIDE HOW I COULD COVER ALL THE ISSUES THAT RELATE TO HOME HEALTH. BUT WHEN I REALLY STARTED LOOKING AT THE WHOLE REALM OF PROBLEMS THEY ALL RETURNED TO ONE BASIC ISSUE. THE WAGE INDEX.

HOME HEALTH REIMBURSEMENT RATES ARE LOW AND THIS DECREASE IN OUR ALREADY LOW WAGE INDEX WILL LOWER OUR COST BY APPROXIMATELY $4.00 PER SKILLED NURSE VISIT. THE WAGE INDEX IS EMBARASSINGLY LOW ESPECIALLY FOR ARKANSAS. ARKANSAS RANKS THE LOWEST OF ALL STATES. WE ARE HALF OF OUR SURROUNDING STATES INCLUDING MISSISSIPPI, OKLAHOMA, LOUISIANA, TENNESSEE, TEXAS AND MISSOURI. WHEN YOU LOOK AT THIS INDEX WE ARE LOWER THAN PEURTO RICO!

THE IMPACT OF THIS DECREASE IN THE WAGE INDEX ON RURAL HEALTH CARE AND RURAL HOSPITALS IN ARKANSAS WILL BE DEVASTATING.

DUE TO THE DRG'S HOSPITAL ADMISSIONS AND STAYS HAVE BEEN SHORTENED GREATLY. PATIENTS ARE DISCHARGED QUICKER AND SICKER. HOME HEALTH CARE IS A LESS COSTLY ALTERNATIVE TO HOSPITALIZATION. HIGH TECH PROCEDURES ARE NOW PERFORMED IN THE HOME. QUALITY OF CARE WILL CONTINUE TO BE TOP PRIORITY IN OUR INDUSTRY.

MANY METROPOLITAN AREAS STATE THAT THEY HAVE THE SAME PERCENTAGE OF MEDICARE AND MEDICAID AS RURAL HOSPITALS. ONE FACTOR IS ALWAYS OVERLOOKED AND THAT IS THAT MANY OF THE MEDICARE PATIENTS IN THE METROPOLITAN AREAS ARE AFFLUENT AND CAN AFFORD TO PAY CO-INSURANCE AND DEDUCTIBLES WHILE IN RURAL AREAS THIS IS RARELY THE CASE. ALSO OUR FAILING INDUSTRY IN RURAL AREAS CAUSES US TO HAVE PATIENTS WITHOUT INSURANCE WHILE LARGER AREAS USE THIS TO OFFSET THEIR COSTS.

WE ARE VERY PROUD TO HAVE THE ADDITIONAL COVERAGE WITH THE MEDICARE CATASTROPHIC COVERAGE ACT DEALING WITH HOME IV THERAPY, BUT MANY PEOPLE ARE NOT AWARE THAT MUCH OF WHAT IS BEING PRESENTED IS ALREADY COVERED UNDER MEDICARE. THIS ACT NEEDS RESEARCH AND THE EXPLORATION OF AREAS THAT ARE NEGLECTED FOR SAFE AND EFFECTIVE TREATMENT TO BE RENDERED.

OUR COUNTRY IS BASED ON A REPUBLIC WHICH USES DEMOCRATIC PRINCIPLES ONE OF THOSE PRINCIPLES IS THE FREE ENTERPRISE SYSTEM. CONGRESS SHOULD BE LOOKING AT WAYS TO ASSIST THE FREE ENTERPRISE SYSTEM. ALL OVER THE WORLD HEALTH PROGRAMS BASED ON GOVERNMENTAL OR SOCIALISM QUASI GOVERNMENTAL SYSTEMS ARE FAILING. IT IS OUR STRONG BELIEF THAT THE COMMITTEE ON AGING SHOULD TAKE A CAREFUL OVERVIEW OF WHAT CAN BE DONE TO ENCOURAGE FREE ENTERPRISE IN OUR COUNTRY.

I APPRECIATE THE OPPORTUNITY TO EXPRESS THE VIEWS OF THE ARKANSAS ASSOCIATION OF HOME HEALTH AGENCIES. THANK YOU FOR YOUR ATTENTION AND CONSIDERATION.

Senator PRYOR. Thank you, Amber.

All right. Ernie Yeager is from Jasper, AR, and we appreciate you being in Little Rock today for our meeting. And you are a retail pharmacist. We look forward to your statement, Ernie.

STATEMENT OF ERNIE YEAGER, MEMBER, ARKANSAS PHARMACISTS ASSOCIATION, JASPER, AR

Mr. YEAGER. Thank you, Senator. It's an honor to be with such distinguished guests here. I don't envy your position of attacking the drug companies. I'm honored to be with such company because I have some of the same feelings that you do on these people. The rash of drug price increases in the last several years has become alarming. Many elderly patients on medications have quit taking medications altogether, and those that can afford some medications have devised methods to let them last longer, usually with devastating results.

Two of the most common tricks used are skipping dosages, taking a tablet every other day instead of every day, or cutting the tablets and capsules in two, making them last longer. The end result is usually a costly hospital stay.

The cost of medications is not only hard on the elderly, but it's hard for any class of people. For example, if a family of three has one child with a positive strep throat culture, usually the whole family has to be treated. This can mean up to five prescriptions. If a drug other than penicillin is used, the cost could be from $75 to $100, and that does not include the doctor's fee. Many times, a parent will purchase only one prescription and try to treat the whole family with the one prescription.

As a pharmacist, I do not enjoy being at the end of the pricing tier, as you explained earlier. I only wish that some of the pharmaceutical executives could justify the 88 percent drug price inflation that has occurred from 1981 to 1988. The general price inflation has risen only 28 percent in the same period of time. Many of these top executives of pharmaceutical firms that have these price increases make in excess of six figure incomes. Many of the people who take expensive medications are on fixed incomes and bring home less than $400 monthly, and I heard even less than that with some of them. To these top executives, maybe $150 is just peanuts. But to an elderly person with a fixed income, spending that much on medication can have devastating results on finances.

Because of the high costs of treatment, many people put off going to the doctor for several months. Sometimes a treatable disease becomes untreatable during this period of procrastination.

When a patent goes off a drug, it surprises me how worthless the manufacturer thinks it is at that point. In the same breath they concoct another salt of the drug and swear it's the greatest thing since apple pie.

I think you will find that much of the money that a pharmaceutical manufacturer spends is not on research but on advertising and promotion of a drug. This again leads to another problem when it comes to "honest data" provided by the very journal that a large pharmaceutical company advertises in. In other words they do not bite the hand that feeds them.

Most medical journals have little if any generic companies advertise in them. As a result, you get very little editorial support for these drugs.

Any monopoly can show ever-increasing profits by raising prices. Most of the profits are not from new drugs, but simply raising prices to the consumer. It does not take an MBA from Harvard to accomplish this. Thank you very much.

Senator PRYOR. Thank you very much, Mr. Yeager.

I may follow on with some questions written to our panelists. I will not ask any further questions at this time. We want to thank you, the four of you, for being here, giving us various phases of the activity in health care that we need to be looking at in the coming months and years ahead.

Our final panel is Mrs. DeMaris Marsh, the State Director, AARP from Monticello, and Mr. Floyd Sexton, member of Arkansas Seniors Organized for Progress from Texarkana. We look forward to both of your statements, and we appreciate your presence. You've had to sit a long time waiting for your turn here, but we appreciate your patience.

MRS. DeMARIS MARSH, STATE DIRECTOR, AMERICAN ASSOCIATION OF RETIRED PERSONS, MONTICELLO, AR

Mrs. MARSH. Thank you, Senator Pryor. I am delighted, as State Director of the American Association of Retired Persons to be able to testify before your commission today. And we want—our membership wants to commend you for holding this hearing and for advancing the debate on long-term care around the Nation. And David, we do know you and we thank you for your long caring for older persons in Arkansas.

Senator PRYOR. Thank you.

Mrs. MARSH. Long-term care is potentially needed for persons of all ages, as we have seen today, not just older persons. This need extends beyond those needing care to family and to friends who provide personal care and financial support. Older Americans from rural areas, in particular, rely upon informal caregivers more heavily because there are no paid providers available in most of our rural communities.

The need for long-term care leads to unmanageable financial burdens because the cost is often enormous. While Medicaid picks up a substantial portion of this, more than half of these costs are paid out of the pockets of residents and of their families. Perhaps most important are the hidden costs of suffering, isolation, and deprivation.

These factors demonstrate the need for a new approach to long-term care, its financing and its delivery. Society already is paying the costs of long-term care, but in ways that place unfair burdens on victims of chronic illness and on their families, as we have heard this morning. AARP recommends a social insurance approach that protects all Americans from impoverishment and from lack of care. By spreading the cost across the entire population, protection could be provided in a more affordable, equitable manner.

A long-term care program that addresses the needs of current retirees and builds an adequate program for future generations will require a range of financing mechanisms. The program also must be self-financed so as not to increase the budget deficit.

Older Americans and the working population will each have to pay some of the costs. Revenues from older Americans could come from higher estate and gift taxes. There could be modest premiums, and there could be cost-sharing in the forms of co-payments and deductibles. Revenue contributed by the working population should be from taxes. It would be earmarked to a trust fund that would build adequate reserves to protect our younger generations, making payroll taxes, probably, the most likely option.

Although private long-term care insurance offers some promise as a way to augment our Federal social insurance program, there are major barriers to this development, including the cost of the policies, the serious limitations and restrictions in coverage. And because of these limits, AARP believes that the primary answer to the long-term care prices lies with the public sector. The private sector approaches should supplement the public system by covering co-payments, deductibles, and extra services. All private sector approaches should also include strong consumer protection standards.

In developing a social insurance system, we must note the special needs of rural populations. The system for delivery of health care in rural areas has always been different, and recent developments have exacerbated these differences, leading to a crisis in rural health care. A major issue is the lack of data, research, and policy analysis relating to long-term care in rural areas.

Another serious concern includes the precise long-term needs of older people in rural America. Improved research could shed light on this.

Second, we need to better recognize the fact that availability of formal community services for people in rural areas differs from those available in urban areas because the range of services is more limited, and within a service, there are fewer alternative forms.

Third, quality of care problems unique to rural areas, such as these in case management, need to be better understood, and that was well done by Herb. Fourth, recruitment of personnel in rural areas can be problematic because young peope often move to urban areas for better job opportunities. We need better information of methods of recruiting and retaining rural health personnel.

Finally, one of the greatest barriers to health care access is the lack of transportation. You've heard about that, too, this morning. Older persons in rural areas often remain isolated. And since home care personnel is not there in their local community, transportation problems increase and so do costs.

In conclusion, long-term care presents a growing national crisis that will touch nearly every American family. The only fair way to provide affordable protection from the devastating costs of long-term care is a broad-based national social insurance program into which everyone pays and from which everyone can benefit.

As I heard the panel this morning, I could not help but feel that you must surely be happy to note that there were several of those people who will be helped by the Catastrophic Act of 1988. For instance, people like Mrs. Trickle will not have to spend down past $12,000 beginning October 1, and she already is getting that skilled nursing home care by having moved her husband across the State line. The prescription drug benefits will kick in at a later time, if we keep those, and they would have helped several of your panelists this morning. The HIV benefit would have helped at least one. And so I know that you are pleased that Congress has already moved in directions to help people in rural, as well as urban areas on this. And in addressing this long-term care crisis, the unique problem in rural areas must always be remembered. Over 6½ million senior citizens live in rural America, approximately 1 out of every 4. Answers to many important rural health research and policy questions are essential.

AARP recommends that increased attention be focused on the unmet needs of the elderly in rural areas, the availability of services in those areas, the quality of care, the health personnel shortages, and transportation issues.

The Association looks forward to working with you in Congress to find realistic solutions to these many problems. Americans, I think, are ready to face the challenge and to protect current and future generations of families from the costs and burdens that accompany the need of the long-term care. Thank you.

Senator PRYOR. Mrs. Marsh, thank you very much.

[The prepared statement of Mrs. Marsh follows:]

AARP

STATEMENT

of the

AMERICAN ASSOCIATION OF RETIRED PERSONS

on

LONG-TERM CARE IN RURAL AMERICA: A FAMILY AND HEALTH POLICY CHALLENGE

Presented by:

DeMaris Marsh,

AARP State Director, Arkansas

Thank you, Senator Pryor. My name is DeMaris Marsh and I am the Arkansas State Director of the American Association of Retired Persons (AARP). On behalf of our membership, I want to commend you for holding this hearing and, by doing so, for advancing the debate on long-term care around the nation. AARP believes that this issue needs careful debate and discussion. We, as a nation, must have a strong commitment to protect persons of all ages against the serious problem of long-term illness and disability. Particular attention should be paid to the needs of people in rural areas.

THE NEED FOR LONG TERM CARE

Long-term care is potentially needed by persons of all ages, not just older persons. Millions of chronically ill children and adults who need long-term care are outside of the current Medicare/Social Security Disability Insurance system and are not covered under private insurance. In addition, as medical technology has advanced, many people who need long-term care are now living longer than they would have in the past. For instance, children with lung disease, who 15 years ago would have died, now are able to live with the assistance of mechanical respirators. They can be dependent on respirators for years. These children represent only one population needing long-term care.

Disability rates increase markedly with age. For example, in 1984, 17 percent of persons aged 65-74 needed help with one or more "basic" activities of daily living, compared with almost 49 percent of people aged 85 or older. Further, since the proportion of older Americans ina community increases as the population within that community decreases, the need for long term care probably is greater in rural areas. For example, in 1980, 12.9 percent of the population of communities outside urban areas with 10,000 to 50,000 inhabitants were elderly, while 15.4 percent of the population of communities with 1,000 to 2,500 inhabitants were elderly.

The need for a new system of long-term care extends beyond those who need the care to those--family and friends - who provide personal care and financial support. Family members are the cornerstone of the long-term care delivery system for the elderly. These caregivers typically provide care every day. According to the 1982 National Long-Term Care Survey, almost 3 out of 4 functionally impaired older Americans rely exclusively on unpaid care provided by families and friends. Another 21 percent rely on a combination of support from families and paid providers. Only 5 percent of the elderly rely solely on paid providers.

Analysts have concluded that olders Americans who live in rural areas may need to rely on informal caregivers more heavily than in other areas because paid providers can be more difficult to find. According to Raymond Coward and Stephen Cutler: "Substantial evidence indicates that the range of services for elders living in small towns and rural communities is more narrow, that fewer alternatives are available within any one service area, and that fewer health care providers exist to offer particular services." ("Informal and Formal Health Care Systems for the Rural Elderly." Health Services Research 23:6 (February 1989), 785-806) Research has not only found that some urban counties have had more services available than in rural counties, but that elders from communities of less than 2,500 persons were somewhat more likely to have helping networks that were composed of family and friends. Additional research has demonstrated that service networks in rural areas tended to have the most significant deficiencies in those types of services likely to be needed by the severely disabled living in the community.

The need for long-term care leads almost inevitably to an unmanageable financial burden because the cost of care is often enormous. The cost of a year in a nursing home averages $25,000. Nursing home stays account for over 80 percent of the expenses incurred by older people who experience very high out-of-pocket costs for health care. Since few people can afford the expense of an extended nursing home stay, many end up on Medicaid after a financial catastrophe has occurred. While Medicaid picks up a substantial share, more than half of nursing home costs are paid out of the pockets of residents and their families. The family's share of this burden has been rising in recent years.

Perhaps most important of all are the hidden costs of suffering, deprivation, and isolation for those in our society who get no care or inadequate help. Data from the National Long-Term Care Survey indicate that large numbers of functionally impaired older persons in the community, particularly the severely disabled, have unmet needs for assistance. For example, 77 percent of older people with three or more limitations in their activities of daily living reported they needed more help.

These factors--the need for long-term care among persons of all ages, the burden on families, impoverishment, and lack of care--demonstrate the need for a new approach to financing and delivering long-term care. AARP recommends a social insurance approach that protects all Americans from impoverishment and lack of care. Social insurance would require financial contributions from all members of society and would provide protection to all who need long-term care. The remainder of my testimony discusses the Association's recommendations for a long-term care program based on social insurance, as well as some of the problems unique to rural areas.

AARP'S RECOMMENDATION FOR A NEW LONG-TERM CARE SYSTEM

Our country's primary governmental long-term care program, Medicaid, is inadequate for several reasons: 1) the Medicaid program does not cover home care except through special waivers; 2) among the services which Medicaid can provide, the degree of coverage varies dramatically from state to state; and 3) because it is a welfare program, Medicaid, often robs families of dignity and independence. Beyond Medicaid, our society is paying the costs of long-term care but in ways that place burdens on the victims of chronic illness and their families. The question before us is how to spread the burden so that the costs to any one person will be small, while offering protection and appropriate care to all. The answer is a social insurance, rather than a welfare, approach.

The nature of the need for long-term care lends itself to an insurance approach based on shared risk for several reasons: 1) relatively few persons in our society need long-term care at any one time; 2) it is nearly impossible to predict who these individuals will be; and 3) the lifetime risk of needing nursing home care is much higher than most people think. (The lifetime risk of institutionalization at age 65 ranges from 36 percent to 63 percent.) This combination of factors shows the need for and the utility of an insurance approach to universal protection. The costs to any one person will be small, while offering protection to all against financial devastation.

Americans of all ages recognize that long-term care protection is a growing necessity. While many underestimate the costs and the likelihood of their needing such service, surveys have demonstrated that the public is willing to participate in and pay for a social insurance approach.

AARP's proposals for long-term health care encompass a number of issues and concerns. All Americans, regardless of age should be eligible for long-term care programs. Nursing home care, day care, and in-home care all constitute particular and valuable resources to severely-disabled Americans who require assistance.

Financing the New Long-Term Care Program

A long-term care program that addresses the needs of current retirees and builds an adequate program for future generations will require a range of financing sources. The program must be self-financed so that it does not increase the federal budget deficit. A financing package should take into account the fact that people at or near retirement would be eligible for benefits before a large reserve fund could be built up. In order to adequately fund the program for future generations, it, like Social Security and Medicare, should be based on social insurance principles. By spreading the cost across the entire population, protection could be provided in a more affordable, equitable manner for any one person.

Older Americans and the working population will each have to pay a portion of the costs of a long-term care program, both in its early phase and for future generations. Revenue from older Americans could come from sources such as higher estate and gift taxes. Modest premiums might be used, but an actuarially sound contribution to buy protection against long-term care costs is simply too expensive for most older Americans. In addition, since any system would likely have some cost-sharing requirements (copayments and deductibles), older Americans would be asked to contribute in this way. Such cost-sharing should, however, reflect the fact that they are already paying substantial premiums for acute care protection under Medicare.

Revenue contributed by the working population should be from taxes that could be earmarked to a trust fund to build adequate reserves to protect younger generations, making payroll taxes a likely option. This could be accomplished through broadening the tax base by uncapping the wage base on the Medicare Hospital Insurance trust fund and by increasing payroll tax rates. This method would allow substantial reserves to accumulate and ensure benefits for the "baby boom" generation. To reassure people under 65 that this is a program for their later years, the fund should be phased-in so that benefits flow primarily to future retirees.

The Association opposes means-testing for eligibility, deductibles, or co-payments for long-term care benefits under an expanded Medicare program. Any flat beneficiary co-payments for either community-based or institutional care services should be modest. People with low incomes should be protected against cost-sharing through an expanded Medicaid-type program, which could be partly financed through general revenues.

The Role of the Private Sector

Private sector options for financing long-term care include private long-term care insurance, home equity conversion plans, and the prospect of long-term care individual medical accounts. Although long-term care insurance offers some promise as a way to augment a federal social insurance program it is still in its infancy and there are major barriers to its development. While the number of policies in force (estimated at 1,000,000) is growing, they cover few of the 51 million Americans aged 55 and over. Projections by the Brookings Institution indicate that the proportion of total nursing homes care financed through private insurance by the years 2016-2020 will be between 7 and 12 percent at most, given favorable assumptions.

This finding is based principally on barriers that are likely to limit the usefulness of long term care insurance policies to the public. Such barriers include:

- the cost of the policies;
- limitations and restrictions in coverage;
- the lack of inflation protection;
- the existence of prior institutionalization requirements as a condition of benefit coverage;
- the lack of adequate home care benefits, and;
- consumers' lack of knowledge about the need for protection against long-term care expenses.

In addition, people in need often cannot purchase private long-term care insurance. Few companies will sell insurance to people age 80 or over, or to people with pre-existing (potentially disabling) medical conditions. This practice may be necessary to maintain the financial stability of the insurance plan, but it leaves those most likely to need long-term care without any protection.

Due to the private sector's limitations, AARP believes that the primary answer to the long-term care financing dilemma lies with the public sector. Under a social insurance system, private sector approaches should supplement the public system by covering copayments, deductibles, and extra services. All private sector approaches should include strong consumer protection standards.

LONG-TERM CARE IN RURAL AMERICA

In developing a social insurance system policy makers must attend to the special needs of people in rural areas. The system for delivery of health care in rural areas has always been different from that in urban areas. Developments over the past several decades -- the failing economy in rural areas, increasing sophistication of medicine and reliance on high-technology devices, and government payment policies for Medicare and Medicaid -- have exacerbated those differences leading to a crisis in the rural health care system.

To deal with this crisis, the unique difficulties in rural areas must be explored. One of the major issues is the lack of data, research, and policy analysis relating to long term care in rural areas. The following issues are of paramount concern:

1. The long term care needs of older people in rural areas. The mortality and morbidity in urban and rural areas differ. The reasons for the variations are unclear. Improved research tools could shed light on this issue. For instance major long term care surveys are not easy for researchers, who are interested in rural issues, to use. Survey data needs to be aggregated by residence or location to facilitate comparisons across various types of non-metropolitan areas.

2. The availability of services. The availability of community services for people in rural areas differs in two ways from the formal services available in urban areas. First, the range of services is more limited in small towns and rural communities. Second, within a service, rural residents have fewer alternative forms from which to choose. The paucity of detailed information about the availability of long term care services in rural areas makes it difficult to make appropriate policy decision about meeting needs in these areas. For example, have hospital closures in rural areas significantly affected access to skilled long term care? How have the financial troubles in the farm belt affected the availability of long term care services? Have differences in the availability of services affected nursing home admission rates for rural residents?

3. The quality of care. In devising new strategies to meet the long term care needs of the disabled population, policy makers have focused little attention on rural America. For example, case management is a relatively new technique used to help people navigate the complex long term care system and help ensure delivery of good quality care. The literature on this service discusses successful case management models but rarely addresses issues of concern in rural areas. For example, there are case managers in Arkansas who have a very difficult time serving their clients in a prompt manner because the clients often live a great distance from one another.

4. The shortage of health personnel. Recruitment of personnel in rural areas can be particularly problematic because young people tend to move to more urban areas that offer better job opportunities. Nursing homes report an eight percent vacancy rate for nurses. Since the Nursing Home Quality Reform Act will require increased nurse staffing the vacancy rate may worsen. Anecdotal evidence suggests that facilities in rural areas will have trouble meeting the new requirements. Thus, we need information about methods that can be used to recruit or retain health personnel in rural areas. In addition, we need to explore how training funds can be used to promote location of health personnel in rural areas.

5. Transportation problems. Arguably the greatest barrier to health care access in rural areas is the lack of transportation. Public transportation is rare in sparsely populated areas. It is costly to operate, benefits few, and cannot be made self-supporting. Without transportation such as a bus system many older persons remain isolated. Since home care personnel generally are not from the local community, transportation becomes a problem and further increases the cost.

The 1980 U.S. Census indicated that greater than 6.5 million senior citizens lived in rural America--approximately one out of every four elders in the nation. Answers to the research and policy questions discussed here are essential if we are to adequately address the needs all older Americans when we consider options for reforming our long term care system. AARP believes that a social insurance approach to long term care can and must encompass the needs of people in rural areas.

CONCLUSION

Long-term care presents a growing national crisis that will touch nearly every American family. Millions of families are vulnerable to financial ruin from the devastating cost of long-term care. Most tragic of all is the suffering, deprivation and isolation of those who get no care or inadequate care.

The only fair way to provide all Americans with affordable protection from the devasting costs of long-term care is a broad-based national social insurance program, similar to Social Security and Medicare, into which everyone pays and from which all can benefit. A social insurance program will make paying for long-term care predictable and affordable. By doing so, it will promote dignity and independence and make it possible for families to avoid the financial disasters that presently accompany chronic illness.

In addressing the long-term care crisis, the unique problem in rural areas must be considered. Clearly, better information on these problems is needed. AARP recommends that increased attention be focused on the unmet needs of the elderly in rural areas; the availability of services in these areas; quality of care; health personnel shortages; and transportation issues.

The Association looks forward to working with the Congress to find realistic solutions to these many problems. We believe Americans throughout the nation are ready to face these challenges to protect current and future generations of families from the various costs and burdens that accompany disabilities and illnesses that require long-term care.

Senator PRYOR. Mr. Floyd Sexton. Appreciate you coming all the way from Texarkana here. You know our friend from North Carolina, the Doctor, Dr. Jim, who just left, he said the thing that he couldn't get over in the State of Arkansas is that in Arkansas, everybody calls their politicians by their first name, and I think that's good. We all know each other, and I appreciate being called by my first name. Thank you, Floyd. You call me David and I will call you Floyd, is that okay?

Mr. SEXTON. Absolutely. Thanks a lot. It's a pleasure to be here.

STATEMENT OF FLOYD SEXTON, MEMBER, ARKANSAS SENIORS ORGANIZED FOR PROGRESS, TEXARKANA, AR

Mr. SEXON. I just wanted to say that after seeing the first panel and hearing their stories and the bit of the film that we saw, I'm not going to try to say anything in the world that will make you think more than they did that we need long-term health care. I do have a short statement that I would like to read. I'll read it quickly and it's rather short.

I am a member, as you announced, of the Arkansas Seniors Organized for Progress. I'm also a member of AARP. I'm here today representing the Long-Term Care Campaign of Arkansas, of which ASOP is pleased to be a part. The Long-Term Care Campaign of Arkansas is new. It has over 20 organizations and is growing, and we are all a part of the National Long-Term Care Campaign. Our membership is as broad as those of us affected by the long-term care problems: seniors, consumers, people with disabilities, organized labor, human service agencies, and religious and civic organizations.

Long-term care is or will be a problem for virtually every American family. It can happen at any time. It could be a grandmother struck down by a stroke or Alzheimer's disease, a child born with cerebral palsy, a teenager hit by a drunk driver, an adult suffering from multiple sclerosis.

And when it does happen, no member of the family is spared. Long-term care is a family problem because Americans deal with it as a family. They all provide care. A child gives up a bedroom so grandma can move in. The family scrimps on expenses so that it can afford some help in the home. There is financial strain, emotional stress. It may be a dreadful decision between help for a child going to college or care for grandma, or a woman who has finally made it into the labor force may have to give up her job and stay at home to help with a loved one.

And I think you know, Senator Pryor, that long-term care has become a genuine issue. No longer is it a problem that families face only as a personal tragedy around the kitchen table that they're afraid to tell their neighbors about. Many of their neighbors have a similar problem. More and more it's becoming a public policy issue, a political issue. Voters feel this issue. They see it as an issue that affects their own family, or one that will. They are worried.

This is really what I am here to talk about, about how folks I know are feeling about long-term care and what we are aiming to do about it.

Now, I'm also here to talk turkey with you, Senator. I am here to tell you that all of us here today aren't about to go home, tell people what a good time we had at this meeting, and go back to our rocking chairs or offices. We older Arkansans and our younger allies are organizing ourselves, putting together our resources, and together with people of all ages across these United States, making the case loudly and clearly for a national response to the problem of long-term care.

We are looking for a response that compares to Social Security in the thirties and Medicare in the sixties. Where Social Security was the first step to dignity for older people and their families and Medicare was the second step, we are now pushing for that third step to dignity, which is long-term care.

Some may say that we are here as a special interest, Senator Pryor, but I know you won't make that misjudgment. We are not here to say, "Please take care of us because we deserve it." Sure we are here as seniors who have needs, but we are also here as parents and grandparents who are conscious of the needs of our children and grandchildren. We are here as voters who have lived a long time and see the need for a comprehensive public program to protect all of us, all of our families.

That's why we senior groups are not going this alone. This is not just our problem, this is a problem that our kids, who are worrying about balancing our generation's needs against the needs of their children. It's a problem for parents who are struggling financially and emotionally to care for a disabled child. It's a problem of many adults who are trying to make a go of it independently without the full use of their bodies or while coping with serious illness. And there are a lot of us senior citizens who are dealing with weak or sick spouses, and even their parents.

We, old and young, are organizing a Long-Term Care Campaign here in Arkansas that is prepared to make our case to our neighbors across the State, to the news media, and to the politicians. We're building a movement of people to tell you that the time has come to face up to this problem.

People are living old. Somebody said 100 years. You know, George Burns said, you know, if you live to be 100, you might never die, because you hardly ever see anyone in the obituaries that die that was over 100 years old.

We believe there is a public concensus that this is the kind of problem that the government can tackle well, just like Social Security and Medicare. We believe that there is a consensus that long-term care is not the kind of thing that we let people deal with alone or that we leave to the private insurance industry. We believe there is a consensus to protect all Americans with a comprehensive public program that will give us piece of mind and be there when we need it, and not leave us prey for some fine print in some insurance policy that none of us can understand. We know there is a cost to this, and we are willing to pay our fair share for the protection we all need.

Hold the applause. I really eat it up when the time comes. With all respect, Senator Pryor, I'd like your Commission to make it clear to your colleagues in Washington that neither we nor the issue are going away. We know this is no small challenge for the

Congress, but you have a unique opportunity to make our case for us, both on the Commission and in the Congress.

We are looking to you for leadership on this. We are looking to you to hear the cries and see the struggles of American families trying to cope against great odds. We are putting our—excuse me. This means a lot to me, and it affects me, I'm sorry. We are looking to you to make—hear the cries and see the struggles of American families trying to cope against great odds. We are putting our faith in you to use your credibility to move this issue forward.

None of us are naive enough, or starry-eyed enough, to think that this will be dealt with overnight. As I've said, we're in this for the long haul. And we ask that you join us in this movement toward the Third Step to Dignity.

We know you are a caring person and astute legislator. We know you don't act without a lot of consideration. So all of us are here today to tell you that as you weigh the merits of this, know that there are a lot of folks back home who are ready to support action on long-term care, and we are ready to pay the price needed to protect our families. I thank you and the Commission for giving me the chance to talk with you today. Thank you very much.

Senator PRYOR. Thank you very much. Well, Floyd Sexton was our 16th witness today. We have had a lot of different ideas—thank you, Floyd—a lot of different ideas expressed. We have heard from those who are actually out there delivering some of the care. We have talked to those who have fallen through the crack and cannot get care, cannot afford that care that is needed. And I can tell you, I think all of us may have a greater and fuller realization at this point, after listening to this this morning, of the complexity and the enormity and the awesome size of the issue and the challenge that lies ahead.

In March 1990, the Commission will make its recommendations to the Congress. I can assure you that no matter what we recommend, it will be a controversial recommendation, mainly because of the dollars that it will take to fuel a program to basically provide health care for those in our society who cannot find that health care or, once again, who fall through the cracks.

It will be very controversial, and it will be a part of the 1990 elections in our congressional seats, in our Senate seats, in our Governors' races around the country, the so-called Pepper Commission report. So we know that you, like ourselves, will continue working on this and other issues that relate. For these people to come and give of their time, provide this testimony, we want to express our depth of appreciation.

There are two I would like to single out today that I have not singled out. I wanted to save them until right at the last. Betty Steed and Rhonda Cunningham have served today as our interpretors for the deaf.

And finally, and definitely I've saved the best to the last here, and the most important person probably in this room is someone who if her function is not completed, all of this would have been in vain. Here we would have sat down here from 10 o'clock until 1:15 in Little Rock, AR talking about all of these problems, but there would never have been printed nor would they have ever gotten to the Pepper Commission members and also the Senate Committee on Aging, and that is our very splendid court reporter, Tammie Foreman. Tammie, we thank you. You put that in that report that I said that.

Ladies and gentlemen, the committee is adjourned. Thank you all very, very much.

[There being no further business before the Commission, the hearing was concluded at 1:17 p.m.]

APPENDIX 1

Item 1

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

OPENING STATEMENT

SENATOR DAVID PRYOR

Chairman, U.S. Senate Special Committee on Aging

before a

Joint Pepper Commission/Aging Committee Hearing on

LONG-TERM CARE IN RURAL AMERICA:
A FAMILY AND HEALTH POLICY CHALLENGE

10:00 a.m. — **The Excelsior Hotel**
August 22, 1989 — **Little Rock, Arkansas**

Good morning. Today, Dr. Jim Davis and I are pleased to convene this joint Pepper Commission/Senate Special Committee on Aging hearing on the issue of long-term care in rural America. For those of you who don't know, Dr. Davis is the immediate past President of the American Medical Association and was appointed by President Reagan to serve as one of the three Presidential appointees to the Pepper Commission.

Considering the extraordinary witnesses and audience we have assembled before us, there is no question that we will have a productive and interesting hearing. No hearing, however, could be a success without the assistance of many dedicated and hard working individuals. Today's hearing is no exception, and before we go to the very important subject at hand, I would like to recognize the work of a number of people. Let me begin with Mary Lou King, who serves as Public Relations Liaison within the Arkansas Division on Aging. Mary Lou has provided invaluable assistance in the development of today's hearing, including the set-up for this beautiful room. I appreciate all your efforts, Mary Lou. Mary Lou's boss, Herb Sanderson, Deputy Director for the Division on Aging, and one of our witnesses this morning, has also lent his tremendous support.

Also, my sincere thanks to Ann Wasson, Executive Director of the Arkansas Association of Area Agencies on Aging; the Chairman of the Commission, Sen. Rockefeller and his fine staff -- in particular, Ed Howard, Steve Edelstein, and Phil Shandler; Jeff Kirsch of the D.C. Long-term Care Campaign, Herb Bingaman and Scott Holladay of Arkansas Seniors Organized for Progress (ASOP), and Cassandra Wilkins with the State Office on Disability, each of whom helped so much with locating our first panel of witnesses.

Let me also take a moment to mention the fine work and assistance provided by the In-Home Services division of the Arkansas Department of Health, and the Area Agency on Aging of Southeast Arkansas, the Central Arkansas Area Agency on Aging, the East Central Arkansas Economic Development Corporation, and the East Arkansas Area Agency on Aging.

A special word of thanks to Ingrid Khanton, Management Project Analyst with the State Division on Aging, who has been a tremendous help to my staff in the preparation of the charts and graphs we have this morning.

A number of people (several of whom are in the audience today) agreed to submit written testimony for inclusion in the official hearing record, including: Dr. David Lipschitz and Dr. Ronni Chernoff, both of the VA Medical Center; Ms. Billie Larch, Executive Director of the Arkansas State Nurses Association; and Mr. Lynn Zeno, Executive Director of the Arkansas Medical Society. I appreciate their willingness to share their unique perspectives on the issue before us this morning.

Just as we cannot put together a hearing like this without everyone pitching in, today's forum will show that we as a society cannot adequately care for our chronically ill family members without an all out team effort from the family, private sector health care providers and insurers, and Federal, State and local governments. We all know that the family caregivers are more than living up to their end of the bargain. But in a team sport, one superstar rarely if ever reaches the victory circle without a supporting cast of players. While the other players are in place, many understandably have questioned the adequacy of their support.

As we will see today, chronic illness and the people it affects knows no age, sex, race or income boundaries. The need for long-term care is therefore a family health care issue that touches and should concern all generations of Americans.

This morning we will hear how chronic illness not only strikes millions of elderly persons, but targets the non-elderly as well. In fact, fully 3.6 million or 39 percent of America's chronically ill population is under 65.

Most of this population will do anything, including foregoing needed care, in order to stay at home. In fact, as the first chart shows, of the 9.3 million Americans of all ages who need long-term care services, 7.6 million or 82 percent reside in the community. And because Medicare and most private insurance plans do not offer significant long-term care coverage, the lion's share of the care is delivered by the family. In fact, as this next chart shows, 74 percent of the chronically ill receive their care <u>solely</u> from family and other informal sources.

What's more, the need for long term care will only increase. The population of persons in Arkansas age 75 and over -- the population most likely to require long-term care services -- grew 17 percent from 1980 to 1985. Moreover, by the year 2000, over half of Arkansas' elderly population will be over age 75.

But this just begins to tell the story. Because the invisible and uncounted victims of chronic illness are the millions of family members who are burdened with the responsibility of caring for their sick and disabled relatives, they are the true heroes of the long-term care saga. For without them, their chronically ill loved ones would have little or no assistance whatsoever.

<u>Who are these heroic caregivers</u>?

- She is your next door 78-year old elderly neighbor who continually provides care to her bedridden husband in the face of the greatest of physical, emotional, and financial odds.
- He is your middle-aged Sunday school teacher who, at a time when he's trying to find the money to finance his and his wife's retirement and help with his children's college education, discovers he will have to find some way to care for his diabetic wife and his Alzheimer's disease afflicted mother.
- They are the parents you rarely see at the PTA meetings because they are taking care of their youngest child who has been diagnosed with multiple sclerosis and, because he works and has a job that does not offer health insurance, they have too much money to qualify for State assistance and too little money to afford an individual private health insurance policy.

These families don't want handouts. Except in the worst cases, they want and, in fact, insist on being the primary caregiver of their loved ones. All they want is some assistance to help them keep their sick family members out of the hospital or the nursing home. Without this help, the caregivers oftentimes become the care recipients. They will go without adequate food, clothing, personal time and, over time, this exacts its own toll. These people need assistance with the costs of home and community based care, nursing home care and the spiraling costs of prescription drugs.

Why are prescription drugs such a problem? Well, in the case of the elderly, four out of five persons have one or more chronic conditions. Consistent with this, over 80 percent of the top drugs most frequently prescribed for the elderly are given for the treatment of their chronic conditions. Because of the importance of these drugs to the chronically ill elderly, it is easy to understand why I believe the new catastrophic health care prescription drug benefit can, and should, be described as a long-term care benefit.

Research just completed for the Department of Health and Human Services found that drug costs are an even more significant factor in bankrupting the chronically ill than home care costs. This fact may astound many people here, but it does not surprise me. The elderly often have to make tough decisions between purchasing the home care they need and the prescription drugs they need. Usually, they decide to purchase the medications and sacrifice their other desperate need -- the need for home and community based care.

What's more, the financial burden of these drugs is increasing and causing more problems. Between 1981 and 1988, the general inflation rate rose 28 percent. During that same period of time, as the chart behind me illustrates, the prescription drug inflation rate rose a staggering 88 percent.

These increased costs, and the proliferation of drugs that do little else but duplicate what is already on the market, threaten not only the newly enacted Medicare prescription drug benefit, but also the health and well-being of the elderly. Increased costs create incentives for the elderly to not follow their doctor's prescription. In order to save money, they stretch out medications and take them only when they "feel bad." Such inappropriate use of these prescriptions leads to more health problems and contributes to unnecessary and expensive hospitalizations and nursing home placements.

The title of this hearing is "Long-Term Care in Rural America." I wanted to hold this hearing to make certain that the Pepper Commission and the Aging Committee members would have access to information that showed that, like most everything else, you cannot develop effective policy without learning about the special populations you will be affecting. Delivering long-term care in rural areas will, out of necessity, require different and creative approaches. Models based on urban successes may well not work.

Rural America is not a carbon copy of urban America. As the chart behind me illustrates, while the elderly comprise 12 percent of the total U.S. population, they account for more than 25 percent of the population of rural America. The rural elderly are twice as likely to be poor as are their urban counterparts. Difficulties resulting from shortages of personnel and inadequate transportation further exacerbate the problems which face rural areas attempting to address the needs of their chronically ill residents of all ages.

These and other problems make the long-term care challenge a difficult and extremely expensive nut to crack. The cost of the care is overwhelming. A new Federal program that would pay for these services would costs tens of billions of dollars. And, although the private long-term care insurance market is beginning to mature, we are told that they will need additional tax incentives to provide the type of policies needed. Even if we did pay for these incentives, most experts feel it is highly unlikely that great percentages of Americans will be able to afford or want to purchase these policies.

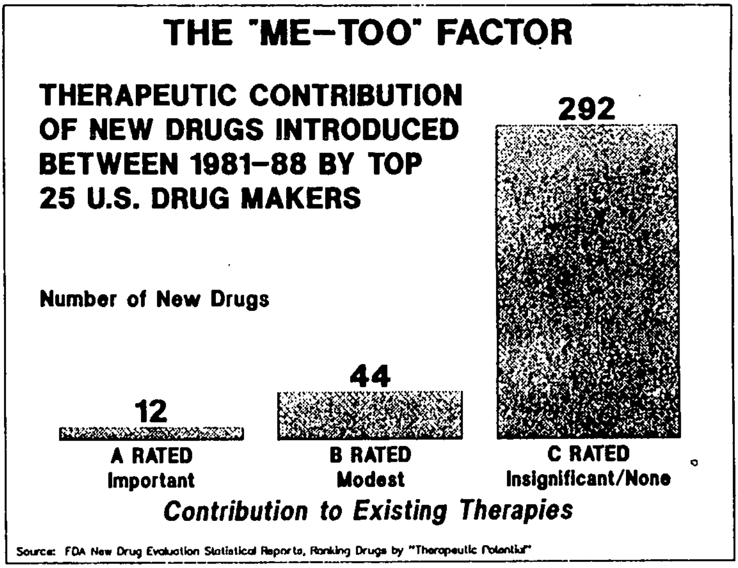
We have two choices now. We can moan and groan about the costs and say it's too difficult a problem to even begin to address. Or, we can work toward developing cost effective, creative and responsive programs to better address the problems of our chronically ill.

I, for one, will not sit back and continue to passively listen to the stories we will be hearing today. In fact, in April of this year I was pleased to join the Chairman of the Pepper Commission, Senator Rockefeller, in introducing S. 785, the Medicaid Home and Community Care Options Act of 1989. Under this legislation, states would be given the option to extend Medicaid coverage for home care services to low-income, functionally disabled persons over the age of 65 without the usual harsh restrictions.

Today, we will hear what other segments of the Federal, State and local governments are attempting to do with the limited resources available. We also will hear how Canada is addressing the long-term care challenge.

But the first thing you will see and hear is an eight minute clip from a recently produced film about long-term care that was narrated by Walter Cronkite. The film, entitled "Can't Afford To Grow Old," is an extremely well done documentary about the issue and it has never been shown in public before. So, in a sense, you are going to see its premiere. The entire film will be aired nationally in early October on PBS.

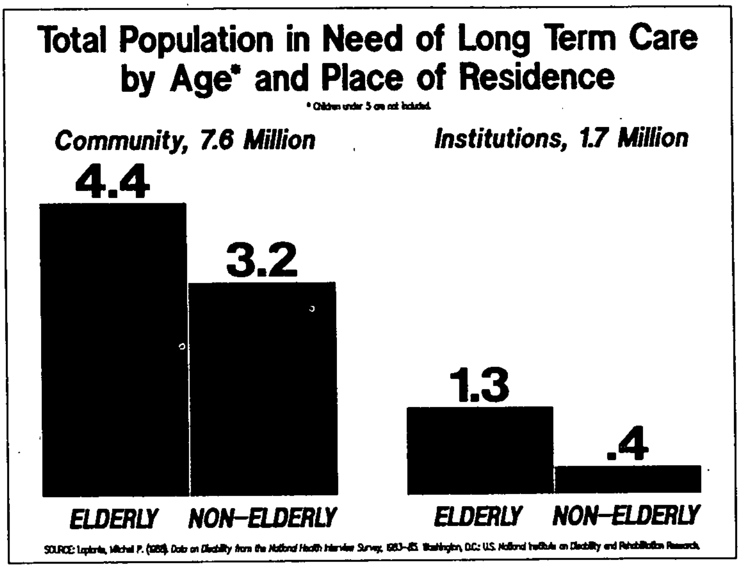
Long-term care is one of the greatest and potentially most expensive health care challenges currently confronting us. To date, we have yet to effectively meet this challenge. The strong support of families of all generations, combined with a real commitment from Federal, State and local governments and private insurers and health care providers, can and should yield responsive and cost sensitive approaches. It is my hope and expectation that this hearing will be one step toward achieving this goal.



THE "ME–TOO" FACTOR

THERAPEUTIC CONTRIBUTION OF NEW DRUGS INTRODUCED BETWEEN 1981–88 BY TOP 25 U.S. DRUG MAKERS

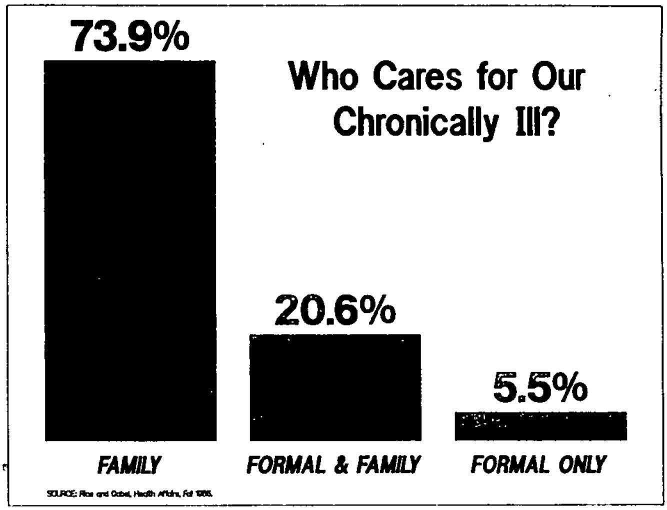
Source: FDA New Drug Evaluation Statistical Reports, Ranking Drugs by "Therapeutic Potential"



Total Population in Need of Long Term Care by Age* and Place of Residence

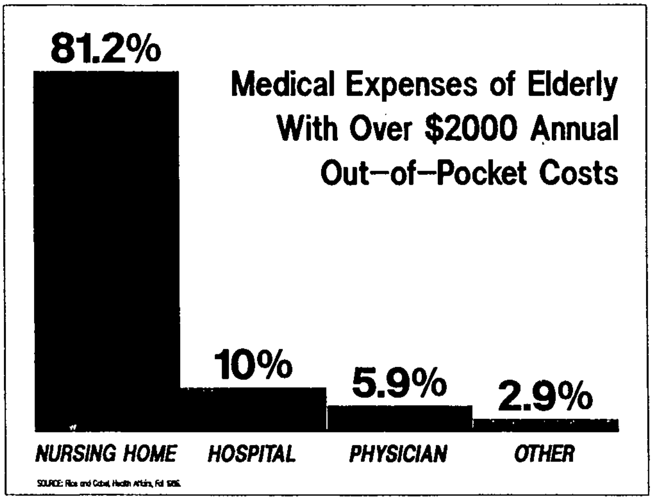
* Children under 5 are not included.

SOURCE: Laplante, Mitchell P. (1988). *Data on Disability from the National Health Interview Survey, 1983–85.* Washington, D.C.: U.S. National Institute on Disability and Rehabilitation Research.



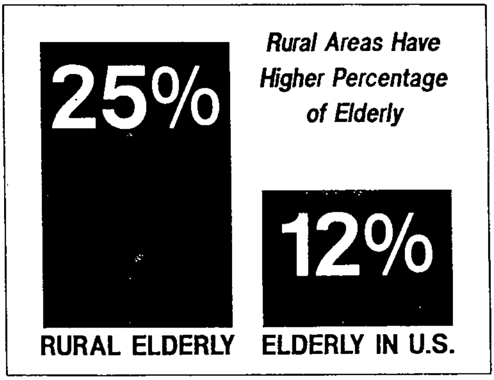
Who Cares for Our Chronically Ill?

SOURCE: Rice and Gabel, Health Affairs, Fall 1986

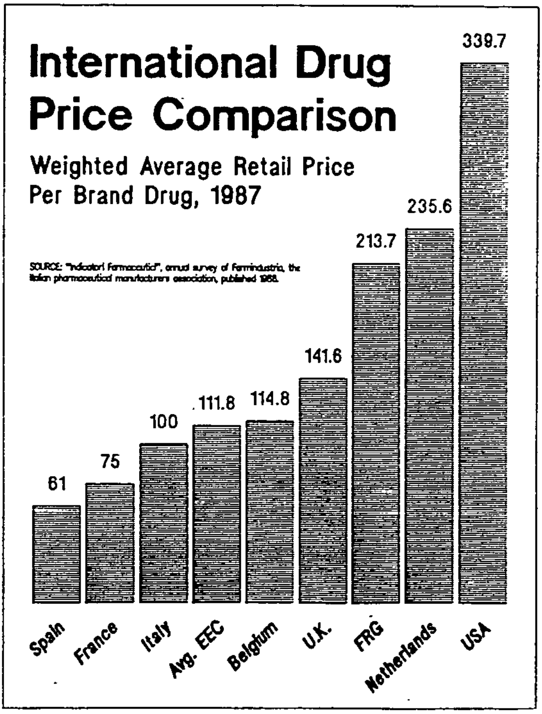


Medical Expenses of Elderly With Over $2000 Annual Out-of-Pocket Costs

SOURCE: Rice and Gabel, Health Affairs, Fall 1986



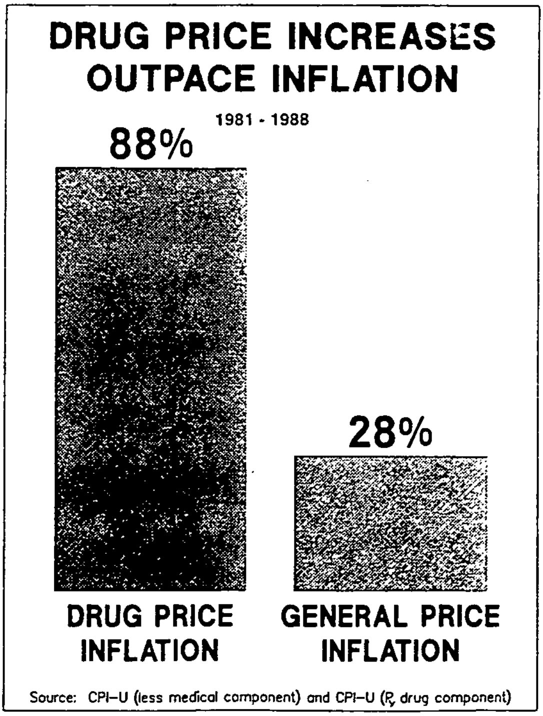
Rural Areas Have Higher Percentage of Elderly



International Drug Price Comparison

Weighted Average Retail Price Per Brand Drug, 1987

SOURCE: "Indicatori Farmaceutici", annual survey of Farmindustria, the Italian pharmaceutical manufacturers association, published 1988.



DRUG PRICE INCREASES OUTPACE INFLATION

1981 - 1988

Source: CPI–U (less medical component) and CPI–U (℞ drug component)

Item 2

CBS
CBS Inc., 51 West 52 Street
New York, New York 10019
(212) 975-4321

August 17, 1989

Dear David:

Thank you for the invitation to speak on the long-term care issue in Little Rock on August 22, 1989.

As was told to Chris Jennings on your staff, my hectic travel schedule will not allow me to be there during that time.

In any case, I hope the film helps to give this issue the credibility it deserves.

Sincerely yours,

Walter Cronkite

Mr. David Pryor
Chairman
UNITED STATES SENATE
Special Committee on Aging
Washington, DC 20510-6400

Item 3

TESTIMONY OF CATHERINE HAWES, PH.D.
BEFORE THE U.S. SENATE SPECIAL COMMITTEE ON AGING
LITTLE ROCK, ARKANSAS: AUGUST 22, 1989

Mr. Chairman and members of the Committee, thank you for offering me the opportunity to speak with you about long-term care. This is a topic of growing importance not only to the elderly but also to those of us who are the children and grandchildren of older persons. We too share some of the joys and many of the worries of our parents as they relate to long-term care. From the outset, let me make clear my position that long-term care is not an "older person's issue." It is first and foremost a family issue.

My name is Catherine Hawes, and I am a Senior Policy Analyst at the Research Triangle Institute. While I take pride in the research on aging and long-term care that takes place at RTI, I wish to make it clear that the views I express here today are mine alone and should not be attributed to RTI or any of its clients.

I have been involved in research, teaching and policy-making in long-term care for 15 years. And now I am joining the ranks of caregivers. Thus I have both a personal and professional commitment to the topic of long-term care.

Today, I would like to take the opportunity to bring you some good news about long-term care and, hopefully, to shatter -- or at least crack -- some myths that have impeded the rational development of long-term care policy in this country.

Recently, in a project for the American Association of Retired Persons, Dr. Rosalie Kane and I analyzed the results of nearly 30 demonstrations of home and community-based care. We also reviewed numerous other studies and the results of some of the Medicaid home and community-based care waiver projects.

The focus of our analysis of these studies and evaluations was not on the issue of cost-effectiveness, narrowly defined. We believe the obsessive focus on costs has obscured equally compelling findings from the demonstrations. Thus, we examined what the results told us about five myths we believe impede the development of comprehensive, rational long-term care policy. There are basically five such beliefs:

1. The "family abandonment" myth:

   If we expand long-term care services, for example by providing public insurance for nursing home care and home care, families will abandon their traditional responsibilities and "dump" elderly relatives on public programs. The assumption here is that the demand for long-term care is a product of family abandonment.

2. The "woodwork" myth, which is now augmented by the "elderly all want maids" myth:

   If we expand home and community-based services, users will emerge out of the "woodwork" and overwhelm the system. Some of this belief in the "woodwork" myth grows out of recognition that there is tremendous unmet need in our communities. Some is a product of the truly vile myth that the elderly simply want "maids" paid for by Medicare or Medicaid.

3. The "nursing homes will vanish" myth:

   If home and community-based care are "successful," the need for and use of nursing homes will disappear, or at least be greatly reduced.

4. The "nothing in home care works" myth.

   Community-based and home care do not "work," that is don't produce any significant benefits. And

5. **The "panacea" or "easy fix" myth:**

A simple solution, a panacea, exists for the problems of long-term care.

During our review of the long-term care demonstrations and Medicaid-waiver evaluations, we asked ourselves what light the results shed on this collection of fixed beliefs or myths. And what we found is notable. The preponderance of evidence from multiple studies, including the most rigorously-designed and carefully analyzed evaluations, is clear about the following:

1. **Families are giving more care, more difficult care, and care over a longer period of time to the elderly today than at any time in our nation's history.** The care they give to older family members often extends for years and covers everything from the most simple tasks, such as grocery shopping and housekeeping, to the most essential and personal activities of daily living, such as feeding and toileting. People repeat the repeated empirical finding that three-quarters of all long-term care in this country is provided by families, but we somehow fail to grasp what this means in daily tasks of responsibility and devotion and weekly hours of incredibly demanding activity -- often by women working full-time outside their homes and caring for their own spouse and children as well.

2. **The bulk of evidence demonstrates that the demand for home and community-based services is both quite reasonable and readily controllable.** The elderly do not emerge out of the woodwork, demanding more and more services. Even in the demonstrations in which considerable effort was expended in recruiting frail older persons to receive services, the more common problem the programs faced was securing sufficient numbers of participants. Indeed, studies are conclusive that the elderly underestimate their needs, relative to the assessments of professionals, and that, on the average, they use far fewer services than their level of dependency and need would predict. Finally, the demonstrations and experience in the Medicaid waiver projects demonstrates that case management programs can be effective in controlling use of services.

The picture of the "greedy" elderly expecting maid services paid for by Medicare is as false and atypical as the myth that the bulk of mothers on AFDC are "welfare queens." The reality for the elderly is that they do lose functional capacities that affect their ability to live independently, and many of the earliest losses of functioning are in the areas of meal preparation, light housekeeping, shopping, and so on. And for those impaired older persons who either live alone or with a similarly disabled relative, their need for assistance in these areas is quite real and is related to physical frailty and often cognitive impairment rather than moral defect.

3. **Home and community-based services are not a broad-brush "alternative" to nursing home care and should not be viewed as such.** First, nursing homes are a reasonable and worthwhile long-term care setting for many of the elderly. The typical nursing home resident today is a widow in her mid-80s, suffering from between three and four chronic diseases and disabilities, typically in addition to incontinence and cognitive impairment. She also has fairly significant impairments in her ability to perform activities of daily living. Half the time, the resident has no close living relative. For such individuals, residing in a nursing home may be appropriate and the only realistic option. Clearly, however, the fact that many people need nursing home care need not imply that homes be organized and operated as they are today.

The second reason that home and community-based care has not shown itself to be an "alternative" to nursing homes is that even in the absence of any home care services, the elderly and their families are extraordinarily unwilling to opt for placement in a nursing home. Families and older persons tend to use nursing homes only when nothing else will do. They have seldom if ever behaved as if keeping the older person at home, with or without services, is a substitute for nursing home care. Instead, nursing home care is an option they use as a last resort. As a result, it is unsurprising that demonstrations that provided home care services often found little effect on nursing home use. But one of the saddest results of family caregiver dedication and the desire for independence among the elderly is that this has allowed some observers to conclude that home care services are unnecessary or ineffective.

4. **The evaluations of home and community-based care have found significant positive results.** These services provide important and highly valued services that enhance the well-being of the elderly. Unfortunately, these positive results are often ignored in the obsession with cost effects. Such positive effects include:

* decreases in unmet care needs;
* increases in contentment and morale; and
* satisfaction with services.

In addition, residentially-based programs, such as congregate housing, were found to reduce nursing home use and total long-term care expenditures. In addition, some of the demonstrations and many of the Medicaid waiver programs have found that a combination of effective screening, low cost program admistration, and a flexible range of community-based services can reduce nursing home use, serve higher numbers of frail elderly, and still reduce or at least not increase total, aggregate long-term care costs.

5. **Finally, we conclude that there is no magic panacea, no easy solution to the problems of financing, cost, quality and access problems in long-term care, but the problems are not intractable.** Case management and private long-term care insurance have recently been heralded by many as "magic bullets." While they may improve some aspects of these problems, they are not panaceas. The following problems, while not intractable, demand serious attention and responses that are as sensitive, flexible, and comprehensive as the problems are complex and challenging.

* The estimates vary; however, between 6.2 and 6.5 million older persons were dependent on others for some assistance in performing the activities of daily living (eating, dressing, grooming, toileting, transfering, and mobility) or the instrumental activities of daily living (such as managing medications, preparing meals, using the telephone or shopping). Eighty percent of these individuals reside in the community.

* While nearly all the community-dwelling dependent elderly receive all or some of their care from family and friends, rather than from formal service providers, as many as 40 percent of the dependent elderly still have unmet care needs. Studies suggest that the more dependent the elderly are, the more likely they are to have unmet care needs.

* Many elderly who need help with basic activities of daily living cannot afford to purchase services to meet their unmet care needs, receive no benefits for such services from Medicare, and are not sufficiently poor to qualify for Medicaid home and community-based services. Approximately four of every ten older persons has an income that is less than 200% of the poverty line, and for these people, the need for long-term care is typically catastrophic.

* For older persons living alone who have to purchase home care five days a week, nearly half would become impoverished within 6 1/2 months. For elderly couples, 22 percent would become impoverished within that time frame, while 33 percent would be destitute within a year. Sixty percent of single older persons would be destitute within a 12-month period.

* Sadly, those most at risk for needing long-term care tend to be the most disadvantaged economically. The elderly with ADL disabilities are disproportionately low income and poor, having many needs and few financial resources. The oldest old and women have the highest risk and the fewest financial resources. Similarly, persons living in rural areas, where services are difficult to purchase in any event, tend to have lower incomes.

* Access to services is a continuing problem. Individuals who become poor in paying for long-term care still face discrimination by providers when they turn to the Medicaid program for assistance. Shortages of beds and even home and community-based services are widely reported. Individuals with serious cognitive deficits and behavior problems also face difficulties in gaining access to nursing home care. Finally, individuals in rural communities face special access problems, since agencies may find it financially unattractive or infeasible to provide services to individuals living in at some distance from a central program location. Programs and case management systems that fail to recognize the higher cost of transportation and the higher unit cost of providing home care services to the rural, homebound elderly or that fail to allow flexibility regarding homecare providers continue to be unresponsive to real but unmet needs.

Thank you again for the opportunity to speak with you today. And let me emphasize again that long-term care is a family issue. The problems of cost, access and quality that affect our elderly relatives are ours also and demand a comprehensive and compassionate response.

Item 4

Long Term Care in Rural America.

David A Lipschitz M.D. Ph.D.

Introduction.

Many rural areas have a large population of elderly persons either because of the presence of large numbers of retirees or migration of younger individuals to urban areas with greater job opportunities. The large fraction of the population that is older, combined with the lack of rural health care manpower and the lack of hospitals, create problems in the delivery of acute care to older rural citizens. In addition, demands for long term care are of necessity higher and resources are at best limited. This testimony will review some of my thoughts of the potential strengths of rural settings as sites for the delivery of high quality long term care to rural elderly Americans.

The Central Role of The Nursing Home.

Fortunately most rural towns and small cities have a nursing home that has the potential of providing adequate care to elderly citizens requiring institutionalization. Furthermore the reduced demand for acute care services in many rural hospitals has resulted in the conversion of a relatively large number of acute care beds to intermediate and chronic care categories. The quality of care provided in the rural nursing home setting is generally superior and usually better than homes serving a largely Medicaid population in an urban setting. The reason for this is almost certainly related to staff stability, greater job satisfaction and more community involvement in assuring adequate care.

These facts make the potential of the delivery of high quality institutional care a reality in many rural settings. However the presence of adequate nursing homes in the rural areas has a number of negative aspects which impact significantly on the way in which long term care is delivered in the entire state of Arkansas, and in many other areas of the United States. The presence of an influential and critical nursing home provider in virtually every small town and district accounts for the tremendous legislative influence wielded by the nursing home industry; it has an agenda frequently at odds with the development of an ideal approach to long term care and alternatives to institutionalization. It is a sad reality that the nursing home industry has frequently created barriers to change in the development of options for elderly individuals who require assistance in their day to day living needs. This is not difficult to understand given the current Medicaid reimbursement patterns for nursing home patients. In

Arkansas reimbursement for a nursing home client with only custodial requirements is virtually identical to that of patients who are functionally dependent and require continuous and skilled care. The presence of a custodial patient population requiring few services is essential for the fiscal survival of most Medicaid-based nursing homes. If all the patients had skilled care needs, staffing needs would be such that few nursing homes would be able to remain solvent. Thus, at the current time, patients who require no more than custodial care account for about fifty percent of the total patient population. Clearly the nursing home industry has a vested interest in maintaining the status quo. If the number of custodial clients were to decrease this would be disastrous for most nursing home operators.

Senator Pryor, this is currently the most scandalous aspect of institutional care in both rural and urban America. If options were available it is very likely that many of these individuals could be cared for in non institutionalized settings. I am sure that you have heard much testimony for the need for alternatives to institutionalization for older frail persons. Suffice it to say that the lack of these services can be linked in part to the rural nursing home industry. Certainly urban nursing homes in large metropolitan areas carry little legislative weight.

An Approach to the Development of Rational Approaches to Long Term Care in Rural America.

The Role of the Nursing Home.

The key aspect to quality long term care is to provide the nursing home with greater financial incentives to care for patients most in need of institutionalization is essential. This will only happen when reimbursement for nursing home patients is tied to their needs. In relation to other states, Arkansas has been backward in not instituting RUGS methodology to create incentives for the delivery of skilled care and disincentives for the delivery of custodial care.

How then will the nursing home manage if they no longer are boarding homes for elderly who may elect other options? It is my strong belief that the nursing homes must be encouraged to become leaders in the design and development of model approaches to the development of alternatives to nursing home care. Why, for example, can a rural nursing home not offer an appropriate Adult Day Care Program that would allow rural families with partially dependent elders to stay in their homes. Nursing homes can also easily provide assisted living opportunities that would be preferable to more traditional institutionalization. Clearly a new industry approach must be developed so that the nursing home lobby becomes an advocate for change. In many ways the development of these programs will be easier and require fewer resources in rural than urban areas.

The Role of the Rural Hospital.

The concept of every rural hospital delivering sophisticated acute care clearly is not a reality. For this reason the rural hospital's survival will depend on the delivery of emergency care and the development of options that provide regional support for patients who require recuperative care. Acute illnesses that in an elderly population are frequently associated with the development of functional dependence. I believe it likely that this change in health care delivery patterns will ultimately benefit rural elderly who may have access to much needed chronic care services that are not available in urban areas. Rural hospitals must be encouraged to develop an identifiable function that will allow them to become critically needed and valued in the health care delivery system.

The Role of the Health Care Professional.

The importance of an interdisciplinary approach to geriatric health care is especially important in the rural setting. Relying and focussing exclusively on the physician shortage and maldistribution of health personnel will not solve the problem of access to care. I would refer you to the most successful Hospital Based Home Care program run by Dr. Rodney Baker at the John L. McClellan Memorial Veterans Hospital. In concert with skilled nurse practitioners and appropriate other health care professionals, this program delivers care to a large number of home bound elderly living in a fifty mile radius of Little Rock. This team approach takes advantage of the special skills of a number of health care professionals and avoids the heavy and unrealistic reliance on physician manpower. There is great need to develop rural interdisciplinary teams capable of providing services to wide and underserved areas. This approach will work whereas attempting to attract a physician to every small town will not, and will prove unnecessarily costly. To design this kind of program there is a great need to provide more training for rural health care professionals. I refer you to the testimony of my colleague Dr. Ronni Chernoff who has addressed the specific educational needs for rural health care professionals. Finally there is a need for more research into methods for development of rational and realistic models to provide the rural elderly with ready access to the health care community.

Conclusions.

The care of rural elderly clearly is a major problem for our society. Fortunately the delivery of long term care services and the design of programs aimed at optimizing functional independence and quality of life are perhaps more easily attainable in the rural than in the urban setting. The role of the rural hospital, the nursing home and the health care team must be appropriately defined to meet this need and in so doing provide for rural health care programs a needed and rational place in our overall health care delivery system.

Senator Pryor I appreciate the opportunity to share my thoughts on this subject with you and the Senate Speicial Committee on Aging. If I can be of any further assistance please feel free to call on me.

David A Lipschitz M.D., Ph.D.
Director Geriatric Research Education
and Clinical Center (GRECC)
John L McClellan Memorial Veterans Hospital
Professor of Medicine
Director Division on Aging
University of Arkansas for Medical Sciences

Item 5

LONG-TERM CARE IN RURAL AMERICA: A FAMILY AND HEALTH POLICY CHALLENGE

U.S. Senate Special Committee on Aging

U.S. Bi-Partisan Commission on Comprehensive Health Care

Certainly one of the challenges to health care professionals and policymakers for the foreseeable future will be the provision of quality health care to our elderly citizens residing in rural areas of the United States. Arkansas can provide a reasonable milieu to develop model programs to address some of the needs identified through these hearings since it ranks second in the nation in the percent population over age 65 years, and much of the State is rural. Based on Arkansas Department of Health data (1988), the rural areas of our State are medically underserved. Arkansas has 75 fewer physicians per 100,000 people than the U.S. average for all physicians. <u>The highest concentration of physicians in Arkansas is similar to the areas that have the lowest percent of the elderly population</u>. Almost three-fourths (74%) of elderly Arkansans live in these rural, medically underserved areas.

It is well-known that individuals over age 65 years are the greatest utilizers of health care resources. Problems reported by this population reflect many chronic conditions that impact on individuals' ability to perform the activities of daily living (ADL), and limitations in access to health care services.

Training primary care physicians has been a major focus of the University of Arkansas for Medical Sciences. Training opportunities in geriatrics for physicians exist but are underutilized by physicians presently in training. Physicians who have had experiential and didactic training in geriatrics are increasing in numbers, but are still very few compared to any other medical specialty. Only a small fraction of physicians practicing in Arkansas have ever had any training in geriatrics. Nursing and allied health professionals have varying levels of formal training in geriatrics, but all agree that there is a rapidly growing need for training and education in geriatrics for health care practitioners in all disciplines as well as for professional faculty to teach them. The high concentration of health care practitioners in urban areas, and the high concentration of elderly people in rural areas, leads to a gap between service providers and the population that is in most need of health care services.

The problems described above are not unique to Arkansas, but exist throughout the country in rural areas. Primary health care is often provided by paraprofessionals, family members, community or agency volunteers, under the direction of a distant health care professional. Access to appropriate resources for information is limited because primary health care providers often do not know how to find the help they need. And, indeed, the help is scarce.

In Arkansas, there are a small number of opportunities to train some of the health professionals (physicians, nurses, social workers, and pharmacists), and limited experiences available to train many of the others (dietitians, dentists, physical and occupational therapists, speech therapists, and audiologists). Virtually all the opportunities exist through training programs sponsored by the Geriatric Research Education and Clinical Center at the John L. McClellan Memorial Veterans Hospital.

One of the limitations encountered in providing educational experiences in geriatrics is the lack of adequately trained and experienced faculty. This is a relatively new area of specialization and there only a few experts in any health discipline to act as preceptors for students, or for faculty training. Compounding the problem is that so many elderly and long term care patients are not in acute care settings where most health practitioner training occurs. Experiences in chronic care settings are either lacking, or only observational, in most curricula for health professions students. The result is that most practicing physicians, nurses, pharmacists, occupational and physical therapists, dietitians, dentists and others have little, if any, experience working with the chronically ill, long term care, elderly patients who are most in need of their expertise and services.

Training programs must be designed to address the needs of existing health care practitioners, preceptor faculty, and trainees or students. Programs must address topics in geriatrics as well as the issues involved with providing health care to a geographically dispersed population such as found in rural America. However, recruitment of students into geriatrics specialty training is difficult. More positions exist, for example, for geriatric medicine fellowships than there are applicants. Applicants, therefore, have their selection of fellowship positions, and usually choose positions at urban medical centers. Geriatric fellowship positions are academically-based, fostering the development of research skills and academic interests, with minimal clinical emphasis. Opportunities for special training for other health care disciplines is limited.

Geriatric Education Centers, funded by the Bureau of Health Professions have filled a part of the existing educational gap. Although we have applied for one several times, we do not have such a program funded in Arkansas. The focus of the most recent proposal, a copy of which was provided to Portia Mittleman in May, 1989 on a recent visit to Little Rock, attempted to address the areas of need specific to rural Arkansas.

Specific suggestions for training were developed to meet the needs of health care practitioners in rural areas. Accessible resources, such as the Medical Information Network at the University of Arkansas for Medical Sciences campus, will have the ability to broadcast educational programs throughout the State, with receiver sites located at locally accessible sites including Area Health Education Centers (AHECs), Department of Health Clinic sites, regional hospitals and, possibly, high schools. Programs would be focused on bringing continuing education programs to rural health care practitioners who are providing primary health care to elderly, long term care, and institutionalized individuals. More experiential training would be provided through the AHECs, regional medical centers and the Health department clinics. Programs would be developed by local faculty through a training program located at the University of Arkansas for Medical Sciences. Local faculty would be trained by experts at the Medical School and the VA Medical Center to develop materials to teach others about geriatrics. Faculty would develop needed expertise in providing care for long term, chronically ill individuals and also gain skills in transmitting the information to practicing health professionals and student health professionals simultaneously.

In the past "train the trainers" programs have worked well. A core of expert faculty is trained in both the content area and in educational techniques, and is expected to pass their expertise on to others. This type of program would also be effective in teaching rural health care workers to train home health aides, family members, and community volunteers to deliver basic health care in rural, medically inacessible areas.

Outreach programs similar to the brief description above are not terribly expensive to develop if cooperation by the sponsoring organizations is encouraged. Arkansas has a unique situation in that the VA and Medical School form a strong core of clinical, educational and research activities in geriatrics which are underutilized by other organizations within the State. The programs that can be developed require creative student recruitment efforts to train future health care professionals, incentives for them to practice in rural areas, support for educational technology development to reach greater numbers of people in remote areas, and a central information center to coordinate the provision of information and outreach program planning.

There is no doubt that there is a serious need for programs to reach the primary health care providers in rural areas of Arkansas, as well as the entire United States. Although efforts are being made by other agencies, the recipients of the available resources in geriatric education are centers where there are high concentrations of medical personnel and minimal concentrations of elderly residents who do not have ready access to the health care and support they require.

Senator Pryor, we appreciate the opportunity to share this information with you and the Senate Special Committee on Aging. Ultimately, all the support programs that may be devised to help those citizens in most need will require that personnel be trained adequately to deliver that care. It is possible to do, and given the opportunity, we believe that Arkansas can serve as a model program and a Center of Excellence in rural health care delivery. Thank you.

Ronni Chernoff, PhD, RD
Associate Director, Geriatric Research Education and Clinical Center
John L. McClellan Memorial Veterans Hospital; and
Professor, Dietetics and Nutrition
College of Health Related Professions
University of Arkansas for Medical Sciences

Item 6

TRANSPORTATION FOR EVERYONE
smts

SOUTHEAST MISSOURI
TRANSPORTATION SERVICE, INC.

120 SO. MINE LA MOTTE
P.O. DRAWER 679
FREDERICKTOWN, MO. 63645
TELEPHONE 314-783-5505

Sparrel Davis, Pres.
Malden, Mo.
Dr. Charles Dare, P.E., V.P.
Rolla, Mo.
Neva Ramsey, Sec.
Neelyville, Mo.
Irene Fallert, Treas.
Ste. Genevieve, Mo.
Wm. E. Osborne, Exec. Dir.
Fredericktown, Mo.

August 18, 1989

Senator John D. "Jay" Rockefeller
C/O Excelsior Hotel
Little Rock, Arkansas

RE. Comments For Field Hearing on Long Term Care In Rural America

Dear Senator Rockefeller;

Please accept my sincere appreciation for the opportunity to address you on these important issues. The personal comments are based on proffessional experience of 15 years as executive director of a rural passenger service system and 8 years experience serving on boards of community hospitals.

The issue is how government can act as a catalyst for change within the quality of life issues. Effectively addressing these issues would be similar to a James Michener novel, so please forgive my failure to include all the history leading to our present challenge. You will find below sectors i feel are important for your deliberation.

1. Individual responsibility

The key stone of a free society is the citizen's acceptance of their responsibilities and duties. It is first peoples responsibility for their actions and well being. Rural America was built on this individualizm particularly the Hill Folk. We must maximize this attitude, help people live more healthy lives and when trouble hits first depending on themselves and family for assistance. Churches and charities were the secondary line of health care providers and can assume this role again. Mother Theresa may have carried the Hospice concept to far for our society, but the concept of quantity of life is more important than quality of life is changing and offers benefits both to the individuals and society.

2. Government investments

To paraphrase Mark Twain "Government can only give you what they have taken away from somebody else". This statement shows the importance of tax revenue. i hope someday the instrument used in tax allocation will be seen less as a budget of expenses and more an investment strategy tool.

Rural America faces many challenges in addition to long term care. Economic development, human resource utlization, natural resources, enviormental and energy conservation goals can be improved through coordination of government investments in long term care.

3. Specific Actions

1. Improve access of rural residents to the goods and services of society through continued support of Rural Public Passenger Service. The Dept. of Transportation's Urban Mass Transportation Administration(UMTA) has proven most effective in implementation of Section 18. You may wish to review the allocation of federal subsidy between rural and urban programs as well as the enviormental and economic benefit derived from these investments.

2. Facilitate the development of a Wholistic family of services available to all rural with special emphasis on the Disadvantaged People. Most Americans have reached the Security level of Maslow's Hiearchy of Needs, development of a planning tool is most important. They can use this tool to consider their future alternatives and plans. To assist their planning process a team of professionals would be available. After their plans are developed, implementation would be done by a certified customer service representative drawn from a human resource pool of unemployed or underemployed rural residents. P.M. Thatcher has been credited with some Public/Private Partnerships along this line.

3. Financing is available for better service, through personal savings, home equity and family resources. Older folks are most concerned about making sure they leave a lot of money to their children and grandchildren, government in some ways may be assisting their efforts. What we need is a group of services so good, the grandchildren, children and customer will invest in seeing that the customer experiences the very best quality of life.

Thank you very much for the honor of speaking before you, i hope these ramblings are of long term benefit to the challenge of long term care for rural residents.

Sincerely,

Wm.E. Osborne

Item 7

Written Testimony of Carolyn D. Rienerth, Executive Director of the Eastern Shore Rural Health System, Inc., Onancock, Virginia

For the Bipartisan Commission on Long-Term Care and
Comprehensive Health Care and the
Senate Special Committee on Aging.

I am honored to have this opportunity to provide testimony for this important hearing on long-term care in rural America. As Executive Director of the Eastern Shore for seven years I have witnessed, as an active participant, the successes bread of our working with the community and sharing efforts with other agencies to maximize our resources and talents. We all work together to provide the best quality of life for our senior citizens. As we see our goals accomplished through everyone working together, we are all the more motivated and assured that these great outcomes are worth every ounce of our effort.

Since 1978, the Eastern Shore Rural Health System, Inc. has provided various and unique programs and services to our geriatric population on the Eastern Shore of Virginia. Because of limited financial resources, we have networked with other agencies in the community who also serve the elderly. We presently provide the usual health care services that all community health centers do, namely, patient education, transportation, pharmacy, following patients in nursing homes, and provide home visits among other things.

The remainder of my testimony will describe a few of our health promotion programs that are specially geared for our senior citizens.

1. We wrote a joint grant with our local Agency on Aging to provide a brokerage model of all the Health and Human Agencies on the Shore. The grant was administered by our local Long-Term Care Council. Every agency on the Council had a staff member represented on the Council. This council staff, consisting of a nurse, social worker, and administrative assistant, provided some kind of service to every agency and the Council. These services consisted of helping the hospital with discharge planning, making home visits and assessments, helping the home health care with Medicaid review, and providing in-service training to nursing homes and health care workers.

Additionally, through this grant we developed a Caregiver's Resource List. This is a list of approved aides that are qualified and available for work. We also have a no cost Durable Medical Equipment Pool to be used as long as needed. The school systems in two counties provided land and liability insurance for construction of two fitness trails for seniors through the grant.

The grant also enabled us to work with the school systems to provide a certified geriatric nurse assistant program that trains people already employed as geriatric nursing assistants in private homes and nursing homes. The course was offered at night so many trainees could upgrade their skill and therefore, improve their employment opportunities. We have had three classes, graduated 60 people, and have a waiting list of eighty!

Although the grant is complete, we have been able to retain most of the facets of the grant.

2. Before we started in the centers there was no structured format for exercise, and no focus on health. One-half of the Seniors were obese and one-third had diabetes. Since we began the program, we now have 50% of the Seniors exercising (anywhere from exercising in their wheelchair, walking with a friend, to aerobic videos specially designed for Seniors).

For the last five years, we have worked with our local Agency on Aging, to provide monthly health education programs for the five Senior Citizens' Centers on the Shore. A different topic is discussed each month, ranging from "Safe Use of Medication" to "Risk Reduction for Cardiovascular Disease." In addition to a Health Promotion/Disease Prevention program, our certified Geriatric Nurse does blood pressure checks, weights, finger sticks for diabetes, and leads in the "stretchies" exercise program.

We now have 98% of them carrying their blood pressure cards an can tell you if they are in compliance with their health care regimines. Through grant sources, other than Public Health Service Act, Section 330 funds, we have been able to purchase physician's scales, blood pressure equipment, glucometers, TVs, VCRs, and exercise bikes for the 5 centers.

3. It has been our privilege to work with the local and national AARP Organization. A few years ago, our organization helped to organize the local AARP Chapter on the Shore that now has 550 members. ESRH's Geriatric Nurse/Health Educator serves as health chairperson for the organization. We organized a Mini-Health Fair and offer regular health education programs. In conjunction with AARP, we sponsor four "55 Alive Driving Courses" per year. This program is a driver refresher course, designed for those Seniors 55 and older who are eligible for a reduction in their auto insurance premium if they pass the course. Our Geriatric Health Educator organized a group of Seniors known as the "Silver Foxes" to walk in the local March of Dimes Team Walk. A special five mile course was set up and many completed the entire course. In addition, they raised $1,300 for the March of Dimes.

4. ESRH also has an Alzheimer's Support Group and Respite Care Program. Through outside resources, we provide eight hours per week of respite care to the caregiver of an Alzheimer's patient. We provide supplies, such as Depends, at no cost to the patient. We have three support groups that meet every two weeks to provide the latest information on this devastating disease. Physicians help educate the caregivers and exchanges of moral support and encouragement are offered. It is a time of sharing ideas and crying on each other's shoulders. In addition, this same team provides in-service training to our three nursing homes to teach how to care for and cope with Alzheimer's patients in their care.

5. About three years ago, one of my physicians challenged our outreach worker to find a way to help some of the elderly patients who seemed to be coming to the health center with vague health problems. This physician did not feel that these frail elderly patients needed mental health services, but that they did need some assistance. In response, the outreach worker met with our geriatric health educator and they formed "The Sunshine Club."

In the beginning the Sunshine Club had about 10 members who met every other Friday at noon. The Mental Health Agency provided a van to pick up the clients and also provided a meeting place. Special activities such as crabbing and quilting parties were planned for each meeting. Many times they brought a bag lunch from home or we provided a lunch for them that they helped prepare.

What we found was that most of their problems were not physical or mental. Instead, they were experiencing loneliness and despair along with a sense of being cut off from other people. Now this group is active and goes to the local nursing home to read to the residents, as well as participate in other activities on the Shore.

Since the development of the Sunshine Club, the same concerned physician commented to one of the members that he did not see her very often in the health center anymore. She informed him that she was too busy and that she did not have time to come to the doctor's office anymore. (This was a patient that would come to the center every week with some complaint.)

We have community volunteers and AARP volunteers who help with this program. One of the volunteers gave one of our members her first permanent in 45 years. Talk about a morale booster. I wish our local, state, and federal program and policy people could see the visible effects that this program has had on the group. These effects sound minor, but when you live alone in substandard housing with no money or transportation, you just cannot imagine how much this has helped the group.

The amazing thing is that this program has cost my organization little money because the community and other organizations have worked together. You can do so much for so little if you are willing to share your resources with other agencies.

I cannot emphasize enough the need for community and health service collaboration and willingness to share resources. As we work together to maximize our resources we will see results. We will see that when everyone works together we can provide the best quality of life for our senior citizens.

Item 8

Testimony of
ARKANSAS MEDICAL SOCIETY
presented to
U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE
Tuesday, August 22, 1989
Little Rock, Arkansas

The Arkansas Medical Society welcomes the opportunity to comment on physicians' concerns regarding the delivery of health care services to the elderly and all other individuals in the United States. Our two biggest concerns involve the ever-increasing elderly population and the often medically underserved rural population in Arkansas. We are particularly concerned with the lack of primary care physicians willing to locate and treat patients in rural Arkansas. We feel that the message the government is sending through current and proposed actions serves as a disincentive for M.D.s to fill this much needed gap in services. We applaud such efforts as the "Rural Primary Care Incentives Act of 1989," however we feel that it will take much more to attract physicians to rural Arkansas for a long standing practice.

Through local efforts we hope to emphasize the importance of family practice within our University of Arkansas Medical School curriculum, and we hope that the U.S. Congress can help alleviate the problems concerning physician reimbursement, the overburden of bureaucratic red tape, and the much misunderstood emphasis on mandatory assignment of Medicare benefits. We also encourage the rejection of the proposed "expenditure targets" currently pending in Washington, D.C.

PHYSICIAN REIMBURSEMENT

Arkansas is unique in that there is no differential in Medicare reimbursement between urban and rural physicians. There is, however, a significant difference in reimbursement to physicians in other states who provide the exact same services as do Arkansas physicians.

The present system is unfair to many Medicare beneficiaries, physicians and taxpayers. All Medicare enrollees have to pay the same amount for Part B coverage. However, those enrollees who live in certain favored parts of the country receive more reimbursement for the same rendered services than do others.

Adopting a more uniform fee schedule would create an incentive for physicians to locate in parts of the country that are underserved.

Following is an example of what Medicare pays for the same procedure in three contiguous states.

	Fort Smith, AR	Broken Arrow, OK	Irving, TX
Code #90050 Office Call	$10.56	$17.60	$23.00
Code #90220 Hospital History & Physical	$59.92	$76.96	$77.60
Code #90250 Routine Hospital Visit	$13.68	$25.52	$33.00

In addition to this discrepancy in reimbursement levels, physician fees have been frozen or severely controlled since June, 1984. Meanwhile cost that they incur, including liability insurance premiums (with an annual average escalation of over 20%) continue to increase.

****

HEALTH CARE FINANCING ADMINISTRATION RULES AND REGULATIONS

Arkansas physicians are burdened (overwhelmed) by the constant barrage of rules and regulations from the Health Care Financing Administration (HCFA), the Medicare Administrative agency.

To detail all the problems would take more paper than we have available and more time than you have to review it.

Directives are received almost daily, which interrupt standard office practice and add additional burden on both patient and physician. This constant bureaucratic, red-tape hassle probably contributes more to non-participation by physicians and discontinuance in the Medicare program than any single reason.

AMONG THE PROBLEMS WROUGHT BY HCFA ARE:

*Complicated formulas and constant harassment regarding a physician's MAXIMUM ALLOWABLE ACTUAL CHARGE (MAAC).

*Constant confusion for patients and physicians regarding procedures used by Medicare carriers in denying claims based on medical necessity.

*Confusion by eligible patients and physicians concerning Medicare/Medicaid crossover claims.

*Confusion in interpreting HCFA directives by the Medicare carriers.

*Confusion and a lack of understanding by patients and physicians over what Medicare will and will not pay for. HCFA fails to properly inform the patient, and the physician gets blamed for it.

*Requirements that referral physicians include on all claim forms the provider number of the referring physicians. These provider numbers have historically been kept confidential and obtaining these numbers from a wide geographic area is time consuming, unneccessary and often very difficult. The Medicare carrier already has these numbers available.

****

MANDATORY ASSIGNMENT FOR MEDICARE SERVICES

The issue of mandatory assignment of Medicare fees is often discussed. This would require physicians to accept Medicare's reimbursement as payment in full and remove their ability to balance bill. The following are reasons that Arkansas physicians are opposed to this proposal and feel that it would further add to the exodus of physicians treating elderly patients.

*Under mandatory assignment, physicians would be limited to collecting Medicare's "reasonable fees". These so-called "reasonable fees" are not reasonable. The rates are unrealistic when compared to the actual cost of providing medical service.

*Physicians have always discounted fees, but on the basis of <u>need</u>. Even though 54% of Arkansas physicians are participating physicians and accept assignment on <u>all</u> claims, 80% of all eligible Medicare claims are accepted by Arkansas physicians as payment in full.

*It is unreasonable and unfair to mandate discount fees purely on the basis of age. Under mandatory assignment, everybody who gets to be 65, even if they are a multi-millionaire, gets a discounted fee (on a standard office visit, Sam Walton can afford the difference between Medicare reimbursement of $10.56 and the average charge of $28.00).

*Many physicians will be forced to abandon or limit their Medicare patients, causing a scarcity of participating doctors. This would especially be a problem to the elderly in areas where there are few primary care physicians.

*The discounts that doctors would be forced to accept for elderly patients will have to be shifted to non-senior patients. Cost will increase for families and for employer-paid medical programs. In many areas of the state there are few, <u>if any</u>, private pay patients to take up this slack in reimbursement.

*Physicians may relocate from or fail to start a practice in areas with a large proportion of elderly people.

****

EXPENDITURE TARGETS

U.S. Senators and Representatives have been inundated with facts and figures from the AMA and a multitude of other medical specialty groups regarding the shortcomings of "expenditure targets". The facts are very clear. The implementation of expenditure targets will result in a rationing of health care for the elderly and will serve as another impediment in efforts to recruit doctors for the treatment of the elderly.

Recent figures from the Congressional Budget Office indicate that the rate of growth in spending for Medicare has declined over the past decade. There are currently sufficient controls through the PRO utilization review to guard against overcharging and inappropriate treatment, and specialty societies are developing practice parameters to further guard against unnecessary treatment. These factors coupled with implementation of the Resource Based Relative Value Scale will insure prudent spending of Medicare dollars.

****

The Arkansas Medical Society shares the concerns of the Bipartisan Commission on Comprehensive Health Care. We encourage the Commission to heed the suggestions of local physicians and to keep the lines of communication open to those practicing M.D.s. Physicians have always been and will continue to be the best advocates for the patients.

For Additional Information Contact:

Z. Lynn Zeno
Director of Governmental Affairs
Arkansas Medical Society
P.O. Box 5776
Little Rock, Arkansas 72215
(501) 224-8967

Item 9

LONG TERM CARE
Senator David Pryor
Little Rock, AR .. August 22, 1989

Martha J. Croy

Re: A Multiple Sclerosis History

DIAGNOSIS:

In 1969, age: 47. Because of areas of numbness in my body, I was diagnosed as possibly having **Multiple Sclerosis**.

By 1973, my balance was becoming effected. Yes, it was definitely **Multiple Sclerosis**. Fatigue was becoming a problem.

By 1975, I was using a cane and needed support when going up and down steps. I could not use a walker as I would fall backwards.
During this time there were changes in my mental attitude: I could not make decisions, have an original thought (that was so frightening), and I had become very serious, even angry (though I denied it).

By 1977, I could not lift my feet to get into bed. My husband, Louis M. Croy, Sr., retired to be with me at night. He traveled for Southwestern Bell Telephone Company. My right foot dragged too much to exercise by walking. Louis made a walking exercising machine for me .. he installed several hand rails over the house and in bathroom. Fatigue was more and more a problem.
By now, I could not stand, and had given up singing in choir, in ensembles, secretarial work, teaching, and other church interest.

1978. I went to The Methodist Hospital in Houston. TX for further tests. Every test indicated Multiple Sclerosis. (I had been in the Baptist Hospital in Little Rock several times.)

In October 1979 **I fell, breaking a foot.** I have been in a wheelchair ever since.

During the Issuing ten years, I gradually lost physical strength and mobility. Each season, and sometimes more often, leaves me with less strength and mobility. I have gradually become unable to cook, clean house, type, play the piano, etc. I have lost the use of my legs and the use of my right hand (I was very right handed, but have become a good left hander now). When put in a chair or bed, I stay in that position until my husband moves me. I have lost the ability to 'push' or 'pull' .. I cannot dress or undress myself .. my speech is becoming slurred. **I have to be lifted from chair to chair to bed!**

In 1988, I lost the ability to "sit". I now "drop" onto seats.

MEDICATION:

I am allergic all prescription medication. Some of those tried were: Dilantin, Baclofen, Valium, Prednisone .. the side effects were much worse than the effects of MS. I have taken Hyperbaric Oxygen treatments (they were helpful for awhile). B-12 shots were effective for awhile also.

My age: 67, weight 135-140 .. my husband's age: 72, weight 190.

We have two children: a son in Birmingham, AL; and a daughter lives here. Our son is too far away to help and our daughter is not strong enough.

Most Important: my husband has an ***Inhuinal Hernia*** that is very painful at times and is dangerous for him to lift me.

My Quality Of Life

I wear glasses, but MS has not caused any eye problems. I read many books, and have a cassette and receive and books from the Library for the Blind and Handicapped, plus the National Geographic. I also receive educational books from the Recording For The Blind in Princeton, New Jersey.

Our kitchen, bedroom and bathroom is 21 inches higher than the rest of the house. In 1979, after I became a permanent wheelchair person, my husband installed a hydraulic lift .. there is a removable 'box' that fits over the steps, the lift raises me 21 inches and I roll out into the kitchen. (As you can well imagine, when I was downstairs, I wanted to be back upstairs or I would need something that was either up or down .. so a lift became a necessity!

A few years ago the National MS Bulletin advertised a "free" IBM used typewriter for therapeutic reasons for MS people .. plus a doctors prescription. We took advantage of that offer - it wasn't "free", but the cost was much less. I type with one finger - left hand! My touch has become lighter and often I do not put enough pressure on typewriter keys to get a print. So, in 1988, we bought a computer, a word processor. It is a wonderful instrument and so very, very therapeutic! I spend many happy hours recording my thoughts, ideas, making notes, writing letters .. I even write letters to my congressmen!

Up to this time, if he feels like it and weather permitting, my husband takes me out everyday. I see and talk to people.

I am truly blessed! I have a clear mind .. I am interested in current events .. I read, listen to tapes or music .. I enjoying seeing and being with people. But, most of all, I have thought, considerate, caring husband!

Listed below are the things my husband has provided for, as needed, from 1969 to 1989:

A wheelchair.
Removed two short walls and two doors.
Made a walking exercise machine to fit my needs.
Built a porch, steps and ramp.
Had an intercom installed.
Installed a Hydraulic lift (to lift wheelchair 21 inches for split level)
Adjustable twin beds.
Cordless telephone.
Cassette - to record messages - I cannot write.
Several hand rails over the house and in the bathroom.
Heavy duty pulleys for arm exercise.
An Omega, an electric 3-wheeler, with a seat that raises or lowers.
An IBM typewriter.
Another wheelchair.
A commercial Passive Exercise Unit (from the Pat Walker Salons .. it was very expensive).
Another cordless telephome.
An answering machine.
Computer with word processor.

I am totally helpless! If anything should happen to my husband, what would I do? And with his Inguinal Hernia, what will happen to him as he contnues lifting me? We cannot get reasonable, affordable help. We receive a pension and social security, which we can live on by being very careful. The cost for help is prohibitive! It is from $7.50 an hour upwards! Insurance will not help, unless I do the following:

To receive any kind of assistance, I must first enter the hospital. I am not ill! Why am I required to enter the hospital an lose strength by being there? Why should my insurance be required to pay for a hospital stay when I am not ill? And then, the help received is only temporary!

WHERE CAN WE TURN FOR ASSISTANCE?

Martha J. Croy
(Mrs. Louis M. Croy Sr.)

Item 10

AEA
ARKANSAS EDUCATION ASSOCIATION 1500 West Fourth Street Little Rock, Arkansas 72201-1064 501/375-4611
SID JOHNSON, President CORA McHENRY, Executive Director

89 SEP -8 PM 1:4

August 29, 1989

The Honorable David Pryor
U.S. Senator
264 Senate Russell Office Building
Washington, D.C. 20510

Dear Senator Pryor:

I attended the Long Term Care hearing in Little Rock August 22nd, representing Betty Kjeldgaard, President of the Arkansas Education Association-Retired. I want to congratulate you and your staff for the excellent format and content of the hearing.

Attached is a copy of a statement by Ms. Kjeldgaard which we would ask be made a part of the hearing record.

Thank you for your leadership and support in this important area. AEA and NEA will work with you in influencing members of Congress to support and vote for needed legislation.

Sincerely,
Richard Hutchinson

Richard Hutchinson
AEA Staff Consultant, AEA-Retired

RH:jab

Statement to the Pepper Commission
August 22, 1989

Thank you for the opportunity to address the Committee on some concerns of great interest to us.

I am Betty Kjeldgaard, a retired teacher from El Dorado, Arkansas. I am President of AEA-Retired, an organization of some 2,000 retired school employees across Arkansas. We are affiliated with the Arkansas Education Association and the National Education Association.

First, I would like to point out that the AEA/NEA Retired organization strongly supports efforts to provide meaningful long term nursing home and home care protection for the chronically ill of all ages. Millions of elderly face financial devastation every year as they and/or their families are hit with disastrous diseases.

Unfortunately, the Medicare Catastrophic Coverage Act passed by the last Congress fails to meet this most pressing need. Further, recent changes in this act proposed by the House Ways and Means Committee do nothing to correct this flaw and also shift even more of the financial burden onto the backs of the poor and elderly.

We support the legislation introduced by Congressman Roybal of California. His "Catastrophic Fairness Amendment" provides a concrete step toward long term care. It also prevents the $50 increase in the annual catastrophic flat premium and moves us back toward Medicare's social insurance financing.

We also believe that now is the time for Congress to begin to develop a national health plan. Health care costs and the cost of health insurance, including long term care, are totally out of control. Thirty-seven million Americans still have no health insurance.

Thank you again for the opportunity to discuss these issues with you.

Item 11

SUNMARK®

MEMORANDUM

TO: SENATOR DAVID PRYOR

FROM: KEITH KENNEDY, PRESIDENT & CEO
THE SUNMARK COMPANIES &
GUARDIAN ADVISORY COUNCIL MEMBER
NATIONAL FEDERATION OF INDEPENDENT
BUSINESSES (ARKANSAS)

DATE: AUGUST 22, 1989

RE: U.S. B I PARTISAN (PEPPER) COMMISSION ON LONG - TERM HEALTH CARE - LITTLE ROCK HEARINGS OF AUGUST 22, 1989

I respectfully submit the enclosed information, which outlines an alternative partial solution to the long term health care.problem. Since the hearings schedule is full and cannot accommodate additional participants I respectfully request this material be filed as part of the hearings.

Sincerely,

Keith K. Kennedy
11809 Jamestown
Little Rock, Arkansas 72211

FUNDING/LONG TERM CARE
-A Partial Solution-

Submitted by:
Keith K Kennedy

I. CHANGING LABORFORCE DEMOGRAPHICS

The changing demographics of the U.S. population present new challenge, opportunities, and considerations for Public Policy.

From 1989 to the year 2000 the following demographic changes are predicted to occur:

- The overall age of the population will increase
- The number of younger workers in the labor force will decrease
- The number of older people (over age 65) will continue to increase
- The aging population will have a major effect on the composition of the workforce
- More workers in the 55 to 64 age group will choose to retire at an earlier date

The implication of these demographic changes are numerous and significant. On the one hand the greater numbers of older citizens will substantially increase the need and cost for more Long Term Care.

At the same time the demand to fill the thousands of new jobs that will likely be created cannot be met by the fewer number of younger people entering the job market. It would appear that many of these jobs can and must be filled by older workers, including many who fit into the contemporary ranks of the retired.

Interestingly enough, the 65/72 age group, many of whom are both mentally and physically healthy represent a highly valuable resource that continues to be largely ignored. Further, social security benefit penalties are designed to discourage most of this group from remaining in (or re-entering) the labor force. A recent *Arkansas Democrat* editorial (4-25-89 attached) estimates that only 10% of retirees work. The article also suggests that some changes in penalty reductions are being contemplated.

II. A NEW APPROACH NEEDED

A more creative and innovative approach is needed to help meet existing Long Term Care needs and in preparing to help meet future Long Term Care needs.

Several ideas would seem worth exploring:

A. Private Sector Incentives

If given appropriate incentives many ordinary business employers would willingly hire from the 65/72 age group and provide them with adequate health benefits, etc. This would effectively eliminate many older workers from this group in need of an alternate funded source of LTC.

Business employers who provided such benefit coverages to older employees could be given special tax credits as an incentive for doing so.

Unfortunately, much of the business sector is extremely wary of government imposing additional employer costs (without their consent) through "off budget" approaches in order to partially achieve government defined social objectives which they view as being largely a public responsibility.

A recent survey (copy attached) shows how high the general level of concern most businesses have regarding further government regulation of the workplace.

Mixing revenue and tax policy with social objectives usually makes for poor Public Policy. A good example of why business concern seems justified is recent IRS regulation Sec. 89 dealing with new employee benefit discrimination tests. It can be summarized as follows:

Its Real Purpose:	To raise additional tax revenues
Its Purported Purpose:	To achieve benefits parity among business owners and workers
Its Likely Result:	Administrative chaos resulting in the scuttling of many employee benefit plans

B. Proposed Payroll Tax Allocation for 65/72 Age Workers

Under this approach, a number of tax law changes would be required. Workers in the 65/72 age group would no longer be penalized for social security reductions because of wages earned. Social security income would be based on age 65 paid in credit, but indexed for cost of living adjustments. The group would continue to pay social security taxes on all wages. The group would not be entitled to receive unemployment benefits.

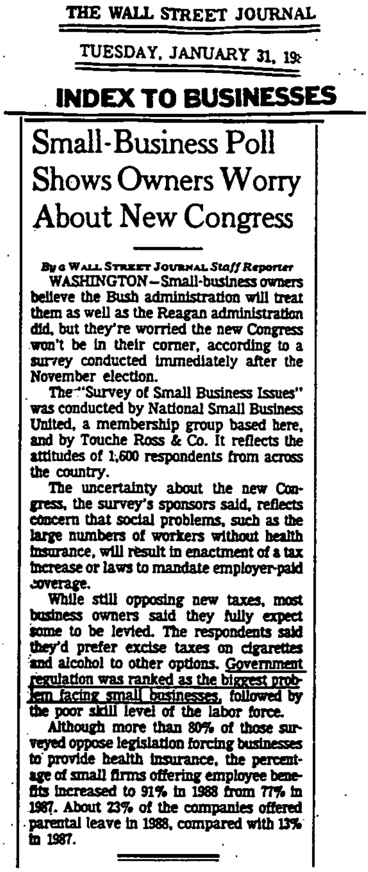
The payroll taxes levied on the wages of this age group would be allocated to help fund a LTC program specifically to help older citizens in need of such financial assistance. Payroll tax sources would include employers' and employees' share of social security (15.02%), plus Federal and State Unemployment Taxes (avg. 2.48%).

III. -A Theoretical Arkansas Scenario-

(Funds Potential)

	Particulars	Assumptions
1.	No. of people age 65 and older	350,000
2.	No. of people age 65 to 72 @ 1/3 x 350,000 =	115,000 Approx.
3.	No. of people age 65/72 willing and able to work @ 1/3 x 115,000 =	40,000 Approx.
4.	Average wage rate paid	$4.50/hr.
5.	Average number of hours worked per week	32 hours
6.	Average weekly wage (32 hours x $4.50/hr) =	$144/wk.
7	Average number of weeks worked per year	42 weeks
8.	Annual earnings of group (40,000 x $144 x 42 weeks) =	$241.9 (million)
9.	Payroll taxes on annual earnings (15.02% + 2.48%) would produce a fund of	$42.3 (million)

-End-



THE WALL STREET JOURNAL

TUESDAY, JANUARY 31, 19

INDEX TO BUSINESSES

Small-Business Poll Shows Owners Worry About New Congress

By a WALL STREET JOURNAL *Staff Reporter*

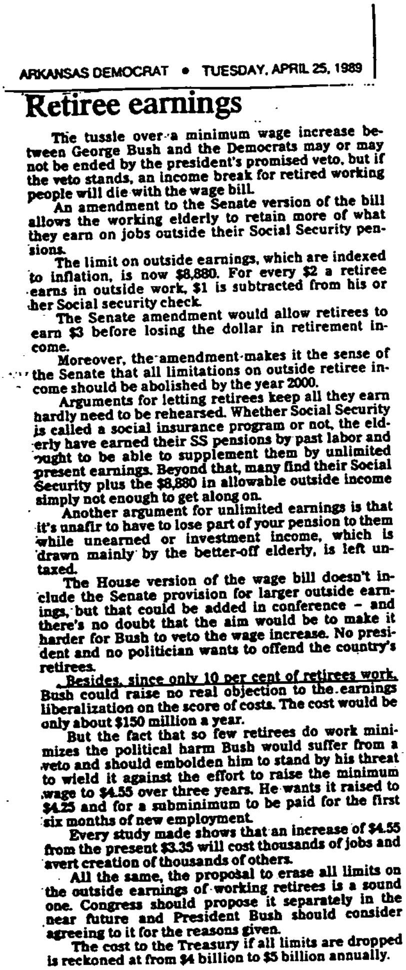
WASHINGTON—Small-business owners believe the Bush administration will treat them as well as the Reagan administration did, but they're worried the new Congress won't be in their corner, according to a survey conducted immediately after the November election.

The "Survey of Small Business Issues" was conducted by National Small Business United, a membership group based here, and by Touche Ross & Co. It reflects the attitudes of 1,600 respondents from across the country.

The uncertainty about the new Congress, the survey's sponsors said, reflects concern that social problems, such as the large numbers of workers without health insurance, will result in enactment of a tax increase or laws to mandate employer-paid coverage.

While still opposing new taxes, most business owners said they fully expect some to be levied. The respondents said they'd prefer excise taxes on cigarettes and alcohol to other options. Government regulation was ranked as the biggest problem facing small businesses, followed by the poor skill level of the labor force.

Although more than 80% of those surveyed oppose legislation forcing businesses to provide health insurance, the percentage of small firms offering employee benefits increased to 91% in 1988 from 77% in 1987. About 23% of the companies offered parental leave in 1988, compared with 13% in 1987.



ARKANSAS DEMOCRAT • TUESDAY, APRIL 25, 1989

Retiree earnings

The tussle over a minimum wage increase between George Bush and the Democrats may or may not be ended by the president's promised veto, but if the veto stands, an income break for retired working people will die with the wage bill.

An amendment to the Senate version of the bill allows the working elderly to retain more of what they earn on jobs outside their Social Security pensions.

The limit on outside earnings, which are indexed to inflation, is now $8,880. For every $2 a retiree earns in outside work, $1 is subtracted from his or her Social security check.

The Senate amendment would allow retirees to earn $3 before losing the dollar in retirement income.

Moreover, the amendment makes it the sense of the Senate that all limitations on outside retiree income should be abolished by the year 2000.

Arguments for letting retirees keep all they earn hardly need to be rehearsed. Whether Social Security is called a social insurance program or not, the elderly have earned their SS pensions by past labor and ought to be able to supplement them by unlimited present earnings. Beyond that, many find their Social Security plus the $8,880 in allowable outside income simply not enough to get along on.

Another argument for unlimited earnings is that it's unafir to have to lose part of your pension to them while unearned or investment income, which is drawn mainly by the better-off elderly, is left untaxed.

The House version of the wage bill doesn't include the Senate provision for larger outside earnings, but that could be added in conference – and there's no doubt that the aim would be to make it harder for Bush to veto the wage increase. No president and no politician wants to offend the country's retirees.

Besides, since only 10 per cent of retirees work, Bush could raise no real objection to the earnings liberalization on the score of costs. The cost would be only about $150 million a year.

But the fact that so few retirees do work minimizes the political harm Bush would suffer from a veto and should embolden him to stand by his threat to wield it against the effort to raise the minimum wage to $4.55 over three years. He wants it raised to $4.25 and for a subminimum to be paid for the first six months of new employment.

Every study made shows that an increase of $4.55 from the present $3.35 will cost thousands of jobs and avert creation of thousands of others.

All the same, the proposal to erase all limits on the outside earnings of working retirees is a sound one. Congress should propose it separately in the near future and President Bush should consider agreeing to it for the reasons given.

The cost to the Treasury if all limits are dropped is reckoned at from $4 billion to $5 billion annually.

Item 12

To: Senator Pryor:

RE: Long term care
Catastrophic Health Bill

Date: aug. 21, 1989.
Public Hearing
Excelsior Hotel

Thank you so much for taking the time to listen to these dear people. Thank you for all you stand for (. your image is that of a giant among the people) Thank you for being honest and someone that can be trusted.

Now, I want express to you one thought. (I shall not be formal or academic in my statement, but shall cut through jargon of the profession and be simple)

Those of us in America
who have something
must accept the
responsibility of sharing
helping those who
do not have as much
as others of us.
We Stated even more
simply:
"Those who will
be paying for health
care i.e. catastrophic Bill
should realize:
The humans who
have will have to
help those who "Have Not".
If we do not give
some help, our nation
is headed 'bad - er times'"

Sincerely
Irene H. Puckett
Legislative Chairman
500 member AARP
Fairfield Bay, AR

Member Governor's
Council on Aging

Item 13

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Greg Gibson, Resource Coordinator, Camp Aldersgate, Inc.

ADDRESS: 2000 Aldersgate Rd.

Little Rock, AR 72205

City State Zip Code

Phone: (501) 225-1444

As Resource Coordinator, working with our senior citizens program at Camp Aldersgate, we have long worked to care for senior citizens in the Little Rock area through a "Day Out" program.

We have in place a program called the "Family Support Project," which works on a case-by-case basis with 15 families in Central Arkansas. The purpose of the project is to help families keep their handicapped child in the home, not only decreasing the costs of care, but also making the situation more desireable for the child and family.

Is their currently a program of this type for senior adults? If we are already doing this for handicapped children & their families, why can we not also do this for senior citizens? Is funding presently available for this type of alternative care, or will this funding become available in the future?

Executive Director: John Blundell
Camp Aldersgate, Inc.
2000 Aldersgate Rd.
Little Rock, AR 72205

Camp Aldersgate

It takes love to understand it...

A Love Story That Keeps Growing

Camp Aldersgate stretches its arms to encircle people who suffer in body, mind or spirit. In its natural 12[illegible] acre setting in west Little Rock, the camp inspires all who enter the gates. Its ministry is especially dedicated to the isolated, lonely and those with handicapping conditions.

[illegible] social service agency of the United Methodist Church, the camp has pioneered such programs [illegible] for the [illegible] camping for children with [illegible] and physical handicapping conditions, respite care, [illegible]ing rehabilitation services, work training projects and programs to improve race relations.

The ministries of Camp Aldersgate have mirrored the [illegible] It has been said that [illegible] about a society by the way it treats the old, sick, weak and [illegible]. [illegible] love story at Camp Aldersgate [illegible] we feel [illegible] and compassion [illegible] that [illegible] Camp Aldersgate [illegible] so does the moral conscience of Arkansans. Camp Aldersgate is a [illegible] those who really care.

Making Time for Those Who Have None

The summer Med Camps, weekend Respite Care and Senior Citizen Programs are FAR MORE THAN a good time for the

kids or a day out for the elderly. These programs [illegible] time for the people who are the caretakers for a handicapped child or adult, [illegible] day in, day out, all year long. They are the real heroes [illegible]. They [illegible] the [illegible] battle the agonies [illegible] constant vigil. [illegible] health [illegible] of their time.

[illegible] responsibility. [illegible] Camp Aldersgate [illegible] Respite Care [illegible] central Arkansas [illegible]

Caring Hearts and Helping Hands

Respite Care is our weekend camping program that runs all year on Friday through Sunday afternoon. Initiated in 1982, it strengthens family relationships by providing structured weekend activities

for disabled family members, and serves as an alternative to institutional care for the disabled.

There is no substitute for the joy and happiness these camping programs bring to participants. One parent said:

"In addition to a professional staff, the program is greatly enriched by the volunteer services of young people who sleep in cabins and assist in weekend activities. There is a nearly one-to-one ratio of staff

...professional and volunteer...to campers.

Summer Med Camps benefit hundreds of handicapped children from all over Arkansas. Nine one-week camping sessions held cooperatively with Med Camps, Inc. serve children with disabilities caused by spina bifida, cerebral palsy, muscular dystrophy, lung impairments, mental retardation, arthritis and other handicapping conditions. Objectives are to encourage fitness, to challenge, to provide these children with a sense of success, to promote

their social and spiritual well-being and to provide compassion and friendship, all under close medical supervision.

We also serve up a hearty helping of old-fashioned fun. When the good times are measured in laughter or in hugs, our Med Camps are total success!

Young Volunteers is a program with a benefit beyond money. Volunteers come to Camp Aldersgate from all over Arkansas to help with the camping programs. Thousands of dollars are saved in wages by their giving thousands of hours in time. There is another benefit that money can't measure ...its the growth and development of young people in public service.

Camp Aldersgate honors these volunteers with a ceremony at the Governor's Mansion where the Governor recognizes the Aldersgate volunteers who have contributed more than 100 hours during the year.

Westside Clinic is a free health clinic offered at Camp Aldersgate each Wednes-

day night from 5:30-7:30 p.m. Health examinations and medical advice are available without charge to anyone in need. It is operated as a cooperative ministry with Catholic Social Services and made possible by volunteer doctors, nurses and pharmacists.

Senior Citizens were offered a nutrition and socialization program at Camp Aldersgate in 1972. Recognized as a model among programs for the elderly, it continues to address the social, spiritual and nutritional needs of senior citizens. Since 1981 the program has been a cooperative effort with the Pulaski County Council on Aging.

Bringing Help and Hope to Dependent Lives

Camp Aldersgate is a special place for special people.

It is a place where a young handicapped person finds acceptance, love and fellowship — and excelling and achieving are still possible.

It is a place where weary caregivers, long on spirit but short on [illegible] their physical and mental resources during the brief respite of care we offer.

It is a place where those in need find free medical advice and care.

It is a place with a history of fighting for the dignity of mankind.

It is rich in the heritage of the principals upon which this nation was founded.

It has weathered social changes and consumer pressures, remained and [illegible] with a mission of love and concern.

On the Statue of Liberty America says to all...

"Give me your tired, your poor, your huddled masses yearning to breathe free... Send these, the homeless, tempest-tossed, to me: I lift my lamp beside the golden door."

More than just a place, Camp Aldersgate is hope for the helpless. It is fun and joy, love and compassion. It's America at its best.

Item 14

THE HONORABLE SENATOR DAVID PRYOR

PEPPER COMMISSION HEARING

LONG TERM CARE IN RURAL AREAS

NEEDS OF THE ELDERLY

1. Lower costs on catastrophic Insurance. This insurance is being paid for by the elderly by withholding on Social Security premiums and taxing the elderly. Since it is available to all ages it should be supported by all age groups.
2. Health care needs to be available for the underinsured and those who have no insurance. Could this situation be made available by a social insurance program?
3. Keep rural hospitals open. Medicare/Medicaid should pay for equal amounts for health care in rural areas as it does in urban areas. Salaries for nurses and other health care providers should be commensurate with the care given which would provide an incentive for professionals to remain in the rural areas.
4. Transportation needs provided for, doctor's visits and other activities of daily living. i.e. grocery shopping, trips to purchase medications, special equipment to maintain themselves, home health chores, lawn care, small home and equipment repairs, etc.
5. Alternative living styles in the community. Group homes have been established in some areas which would permit groups of 6-10 people to live together and support themselves on Social Security/SSI income. No live in supervision is necessary. Salaries of four licensed nursing personnel could adequately provide daily visits. These salaries could come from state funds. (See article attached.) This program is now 23 years old and is viable and meeting the needs of people who have no families, friends, or other resources. The salaried person makes daily visits to make certain that the group members are taking prescribed medications, are well, proper nutrition is maintained, homes are clean and orderly, and to assist

the group if some one is ill and needs treatment. The group member is accompanied to the physicians office and returned to his home. It is the duty of this person to make sure the person understands the physicians orders and carries them out appropriately. This program was originally set up for the chronically mentally ill in institutions to allow them to be returned to the community, earn their own living, and become tax paying citizens with equal rights as their neighbors enjoyed. At this point in time the members are older (up to age 82) and are continuing to maintain themselves with very little financial support from the state. There are other homes in other states that have group homes for the elderly.

6. Redesign nurses homes to meet the needs of the client. If a person cannot be maintained in the home, either by himself or with the assistance of others, and his disabilities are physical as the result of a disease process, then a properly designed nursing home could meet those individual needs. (See attached paper which was presented at the 31st Annual International General Systems Research meeting, May 25, 1988 at the Omni Hotel in St. Louis, Missouri. This paper co-authored and presented by Patricia Trussell, Ph.D., R.N. and Billie Larch, RNC, MSE, MA.)

7. This speaker had the opportunity to function as a member of an investigation team October 28, 29, 30, 1989. The team was composed of four people; one gerontological nurse and three members of Attorney General Steve Clark's office from the Medicaid Fraud Division. These investigations were a part of the Nursing Home Reform program in Arkansas. Eight homes were visited over a two-day period. Findings were made public and the nursing home regulatory agency of the Department of Human Services was asked to take action. Two instances of life-threatening patient abuse necessitated the immediate removal of two nursing home residents to hospitals. One of the nursing homes which this speaker

visited had 138 residents. Many horrible conditions were revealed by administering a head to toe nursing assessment. An abstract of a paper was submitted to the American Society on Aging for acceptance of a presentation based on these visits at the 36th Annual Meeting to be held April 5-8 at the San Francisco Hilton Hotel.

This is only a mini list of needs of the elderly. These were selected to present as written testimony due to the extensive involvement that the speaker has had in 26 years of nursing experience.

Respectfully submitted,

Billie Larch, RNC, MSE, MA
Executive Director, ASNA

Small Group Work Therapy for the Chronic Mentally Ill

Larry R. Faulkner, M.D.
Bentson H. McFarland, M.D., Ph.D.
Billie B. Larch, R.N., M.S.E.
Wanda Jean Harris, L.P.T.N.
Charles D. Yohe, M.D.

In 1980 the authors reviewed the records of the first 130 patients to enter small group work therapy, a program begun in 1964 by Arkansas State Hospital and Arkansas Rehabilitation Services in which chronic schizophrenic patients live in group homes and work in Hot Springs. Forty-five of the original patients were still in the program in 1980. Although the patients had been hospitalized for an average of 11 years, they spent an average of seven years in the program, during which time their hospital utilization dropped significantly. Forty-two were discharged to settings offering greater independence. The authors focus on the role of a rehabilitative unit of Arkansas State Hospital known as the HIP unit, which, until it was closed in 1976, prepared patients to live and work with each other before entering small group work therapy.

In recent years the chronic mentally ill have been the subject of much discussion and debate (1,2). Studies have attempted to define and characterize chronic patients (3,4) and to describe programs and principles for their treatment and rehabilitation (5–7). While many of the studies have significant methodological problems (8), their conclusion that well-designed and well-administered community programs are effective is generally accepted (9,10).

The community lodge developed by Fairweather and his associates (11) in Palo Alto, California, in the mid-1960s is an example of a model program for chronic patients. Fairweather believed that chronic patients needed a new social subsystem that was supportive and protective but encouraged as much autonomy and individual functioning as possible. He also recognized the importance of productive work in developing an individual's identity and sense of personal worth in society (12–14). Through the prototype lodge, residents were taught to live together with minimal professional supervision and to run their own janitorial service. Controlled research revealed that the lodge society significantly reduced hospital recidivism, improved employment, and lowered treatment costs (11).

Fairweather and his associates (15,16) encouraged other programs around the country to develop modifications of the lodge prototype. While most replicas of the community lodge met with only limited success, one of the first, small group work therapy, which was begun in Arkansas in 1966, is an exception (17). In this paper, we describe the development and evolution of small group work therapy and present data describing the characteristics and history of the original 130 patients placed in the small group work therapy program. We conclude with a discussion of the data and present what we believe to be the major reasons for the program's success.

Development and evolution

The small group work therapy program evolved through an effort to reduce the population of the Benton psychiatric unit of Arkansas State Hospital, which in 1964 was about 2,000 patients. In 1964 Arkansas State Hospital received Hospital Improvement Program (HIP) funding from the National Institute of Mental Health for the creation of a 72-bed unit at Benton that would prepare patients to live in the community. The unit was located in an existing building that was remodeled to be as homelike as possible. Staff of the Hospital Improvement Program unit included one psychiatrist, one psychologist, two social workers, two registered nurses, one occupational therapist, one recreational therapist, one beautician, and 18 licensed psychiatric technicians.

All referrals to the HIP unit were screened by the psychologist for at least some rehabilitation po-

---

Dr. Faulkner is director of education, assistant director of the community psychiatry training program, and associate professor of psychiatry at Oregon Health Sciences University, 3181 Southwest Sam Jackson Park Road, Portland, Oregon 97201. Dr. McFarland is a Milbank scholar and assistant professor of psychiatry at the university. Ms. Larch is nurse consultant, Ms. Harris is program director, and Dr. Yohe is consultant psychiatrist for Small Group Work Therapy, Inc., in Hot Springs, Arkansas. Ms. Larch is also associate chief of nursing education at the VA Medical Center in Little Rock.

tential, although they all were considered to be poor candidates for rehabilitation by Arkansas Rehabilitation Services. In addition, only patients who had been in Benton for at least five years were accepted. Each patient was thoroughly evaluated and provided with a multidisciplinary treatment plan, a combination of individual, group, occupational, and recreational therapies as well as structured social activities. Medications were continued as before.

At the end of the HIP unit's first year of operation, staff were convinced that the unit had significantly improved patients' hospital adjustment. However, only about 20 percent of HIP-unit patients had been discharged. After a search for new treatment techniques for rehabilitation of chronic patients, HIP staff decided that the Fairweather approach seemed best suited to the needs of the patients. A Fairweather associate was consulted to help orient HIP-unit staff and discuss potential problems and solutions. There was some concern that HIP-unit patients would be more difficult to rehabilitate than those in Palo Alto because they were older, were of both sexes, lived in a rural area, and had been hospitalized more than twice as long. Despite these concerns, staff decided to proceed.

The basic plan was to organize patients into groups that would live and work together on the HIP unit. When all the patients in the group had achieved a certain level of skill in group living, they would be discharged as a group to live in the community, where they would work and seek to become involved in community life.

In November 1965 HIP-unit patients were divided into four groups of 15 patients. Following the Fairweather technique, before leaving the HIP unit to live in the community, patients were required to progress through four levels of increasing responsibilities and privileges. At each level they were expected to take care of their personal needs, including grooming themselves, cleaning their bedroom, doing their laundry, and taking their medicine. Each group had responsibility for preparing group meals, developing a valuable skill that would lead to employment in the community, and governing themselves, including identifying a leader. Group members evaluated one another on their performance in these areas, and staff provided feedback to each group once a week concerning their performance as a whole.

HIP-unit staff collaborated with Arkansas Rehabilitation Services to provide job training for patients while they were still living on the HIP unit. These two groups also formed a nonprofit corporation named Small Group Work Therapy, which worked out agreements with community employers for hiring patients, collected money for patient services, distributed funds to patient groups, and protected patients from exploitation.

Within six months of entering the HIP unit, 40 of the 60 patients were felt to be ready for discharge to the community. Hot Springs was selected as the site for the community phase of the project for several reasons. It is a retirement and resort town that has many potentially good employment sites for patients; the HIP psychiatrist was from Hot Springs and knew many of the community and business leaders; there was an active local mental health association that would serve as a resource for patient support; and local citizens were accustomed to coexisting with handicapped people because Arkansas Rehabilitation Services operated a large rehabilitation center in Hot Springs.

The HIP-unit psychiatrist, nurse, and social worker visited potential employers in Hot Springs and had surprisingly little difficulty convincing them to hire patients. Several incentives contributed to the success in obtaining employment contracts. First, patients would receive specific on-the-job training at no cost to the employer; second, patients would not be placed on the payroll until they demonstrated acceptable job performance; third, employers developed contracts with the small group work therapy corporation rather than with individual patients; and fourth, the Arkansas Department of Labor had agreed to certify a number of patients as handicapped workers and to set a fair wage for their work (18).

The employment contract between the work therapy corporation and employers stipulated that an entire patient group would work for the same business, performing a variety of specific jobs. Each member's job depended on his or her work potential, and there was flexibility in shifting members from one task to another. Each employer paid the corporation monthly with one check for all services provided by the group.

If individual members were unable to work or employment became unavailable, community coordinators helped them apply for Social Security benefits. Through employment or Social Security, each group member would eventually be able to become relatively self-sufficient.

Once employment contracts were obtained, HIP-unit staff moved four groups into the community during the summer of 1966. Groups continued to function in the community as they had on the HIP unit at Benton. Group members had specific responsibilities in the community home, such as planning, shopping for, and cooking meals; cleaning up; keeping house; and doing yard work and bookkeeping. Members' performance was monitored by the group.

Two licensed psychiatric technicians who had been with the HIP unit from the beginning served as community coordinators. They monitored individual and group performance and served as liaisons with employers. The HIP-unit psychiatrist continued to see group members regularly for medication management. As each group assumed more and more responsibility for its functioning, the involvement of community coordinators diminished, although they continued to visit each group daily. Groups were encouraged to make use of community services and recreational activities as much as possible and to avoid programs that emphasized their emotional disabilities or that were contrived especially for psychiatric patients.

Within two years 13 groups had been formed in the community. Subsequently patients were discharged from the HIP unit individually to fill group vacancies. In 1976 the HIP unit was closed because the supply of potential patients at Benton who were candidates for small group work therapy was exhausted. Since then referrals to the groups have been made directly from Arkansas State Hospital or from community mental health centers. Recent referrals have not had the benefit of prior training in group process and at times their adjustment has been more difficult. Members of the same group no longer work for the same employer, but residence in the same home has helped members maintain group cohesion and problem-solving abilities.

With the addition of more groups and the closing of the HIP unit, the small group work therapy community staff was increased. In 1980 staff included a part-time psychiatrist (40 percent full-time equivalent), a part-time registered nurse consultant (15 percent full-time equivalent), and four full-time licensed psychiatric technicians, one of whom served as the program coordinator. The psychiatrist, registered nurse, and program coordinator had been with small group work therapy since it began and were instrumental in its design and development.

From 1966 to 1980 about 550 patients were treated in the small group work therapy program. In July 1980 nine groups were living in the community with a total census of 83 members. The 1980 operating budget of the small group work therapy corporation was approximately $257,000. The corporation itself provided $161,000 of the funds, which were obtained from patient salaries, Social Security benefits, or other resources. The Arkansas Mental Health Division provided the remaining $96,000, which paid for staff salaries, fringe benefits, and transportation of group members to and from their jobs. The total cost for each group member was about $3,200 per year, or $8.80 per day. The cost per patient to the mental health division was about $1,200 per year, or $3.30 per day. By comparison, in 1980 the daily cost for a patient in a state hospital was about $100, and for a patient in an intermediate care facility about $140.

Characteristics and history of the original patients

In July 1980 one of the authors (LRF) reviewed records kept by the HIP unit and the small group work therapy program on the first 130 patients released from the unit to a small group work therapy home. All the patients had been admitted to small group work therapy by July 1970. On July 1, 1980, another author (WJH), who had extensive knowledge of the original small group work therapy patients, evaluated the activity levels of 50 patients still in the program using a modified version of a scale developed by Sandall and associates (19). Forty-five of the patients continued to live in a small group work therapy home, but five were living in the community under the supervision of staff of the work therapy program.

For all 130 patients, data were available about selected demographics; diagnosis; medication use; days spent in the program; hospitalizations before, during, and after entering the program; initial placement after small group work therapy; and location on July 1, 1980. For the 50 original patients still in the program on July 1, 1980, activity levels were also available. Follow-up data were available for discharged patients, who had been followed for an average of approximately 12 years after they were discharged.

Patient data. At entry into small group work therapy the original 130 patients had a mean age of 42.7 years and a median age of 43 years. Fifty-four percent were female. Ninety-one percent were Caucasian, and 9 percent were black. Forty-eight percent were single, 47 percent were divorced, 5 percent were married, and 1 percent were widowed. They had a mean educational level of 8.6 years. Prior to entering small group work therapy, patients had been hospitalized an average of 4.5 times and had spent an average of nearly 11 years in the hospital.

Seventy-six percent of the patients were schizophrenic, 19 percent were mentally retarded, 3 percent were manic-depressive, and 2 percent had organic brain syndrome. Ninety-three percent were prescribed antipsychotic medications, 12 percent were prescribed antidepressants, and 3 percent were prescribed antianxiety agents. Five percent received no psychotropic medication.

Length of stay and initial placement. Nine patients died while in the work therapy program, which was consistent with the mortality rate of the general population of Arkansas (20,21). Seventy-six patients were discharged from the homes, and 45 remained in the group homes as of July 1, 1980. The mean length of stay for the original 130 patients was almost seven years. The mean length of stay for the discharged patients was almost four years; for the patients who remained in the program it was more than 12 years.

Forty-two patients (32 percent) were initially discharged from the group therapy homes to settings that offered greater independence than the work therapy homes, such as living with their family, on their own, or in an independent living arrangement. Thirty-four (26 percent) of the discharged patients were placed in settings such as the state hospital or a nursing home that offered less independence than the program's community homes. To be conservative, we grouped patients who eloped with patients placed in less independent settings, even though their initial

Table 1
Initial placement of 121 patients after discharge from small group work therapy and placement on July 1, 1980

Type of placement	Initial placement N	Initial placement %	1980 placement[1] N	1980 placement[1] %
Remained in small group work therapy residence	45	35	45	35
More independent setting	42	32	39[2]	30
With family	24	18	24	18
In community with no staff supervision	10	8	10	8
In community with staff supervision	8	6	5	4
Less independent setting	34	26	25[2]	19
State hospital	28	22	4	3
Elopement	3	2	—	—
Nursing home	3	2	21	16

[1] Six patients died in the period between initial placement and July 1, 1980, and six were lost to follow-up.
[2] A significant correlation was found between a patient's initial placement and his placement on July 1, 1980 (χ^2=32, df=1, p<.001).

placement was unknown.

There was no significant difference in the mean length of time spent in small group work therapy by the patients who were discharged to more independent settings and by those who were discharged to less independent settings.

We found a significant correlation between patients' initial placement after discharge from small group work therapy and their location on July 1, 1980, indicating that patients did not become significantly more or less independent between the time of their first placement and July 1980; see Table 1.

Multiple regression analysis indicated that the number of times a patient was hospitalized before admission to the work therapy program (r=−.22, p<.05), a patient's age at entry into the program (r=−.22, p<.05), and whether a patient had ever been married (r=.21, p<.01) were predictive of initial placements offering greater independence than small group work therapy. These factors explained 17 percent of the variance in initial placements in the two categories and accurately predicted the placement of 74 percent of the patients.

Variables that predicted placements with greater independence on July 1, 1980, were a patient's age at entry into small group work therapy (r=−.29, p<.01) and years of education (r=.24, p<.05). These factors explained 15 percent of the variance in placement in the two categories and accurately predicted the location of 69 percent of the patients.

Hospitalization before, during, and after small group work therapy. The mean number of hospitalizations, the mean total time in the hospital, the mean length of stay per hospital admission, and the mean percentage of time spent in the hospital all decreased significantly during patients' participation in small group work therapy; see Table 2. After discharge from the program, patients tended to be hospitalized more frequently and for longer periods but still significantly less than before admission to the program.

While participating in small group work therapy, 67 patients (52 percent) did not return to the hospital, 31 patients (24 percent) were hospitalized once, 23 patients (18 percent) were hospitalized twice, four patients (3 percent) were hospitalized three times, four patients (3 percent) were hospitalized four times, and one patient (1 percent) was hospitalized five times.

Multiple regression analysis revealed that the only known variable that predicted the number of hospitalizations during small group work therapy was mean days in the program. Patients who spent more

Table 2
Comparison of mean (±SEM) percentage of time spent in hospitals by 121 patients before, during, and after participation in small group work therapy, by initial placement

Initial placement	N pts	Mean percentage (±SEM) of time in hospital			Before vs. during			During vs. after			Before vs. after		
		Before	During	After[1]	t	df	p<	t	df	p<	t	df	p<
Remained in small group work therapy residence	45	25.6±2.3	2.4±0.7	—	8.2	44	.0001						
More independent setting	42	22.6±2.2	7.5±2.3	6.9±2	5.15	41	.0001	.22	41	ns	4.83	41	.0001
Less independent setting	34	21.9±2.8	4.4±2.1	19.5±4.5	5.37	33	.0001	2.99	33	.01	.4	33	ns

[1] One-way analysis of variance found a significant difference in the mean percentage of time spent in hospitals after discharge by patients initially placed in a more independent setting and those initially placed in a less independent setting (F=7.51, df=1, 74, p<.01).

time in the program had more hospitalizations.

There were no differences in the percentage of time spent in the hospital before and during participation in small group work therapy between patients who had been initially discharged to a setting offering greater independence and patients initially discharged to one offering less independence. However, as Table 2 indicates, patients whose initial placements offered more independence spent significantly less time in the hospital after discharge from small group work therapy than those whose initial placements offered less independence.

Although patients in both groups spent significantly less time in the hospital during their participation in small group work therapy than before it, only patients whose initial placements offered greater independence continued their low hospital utilization after discharge from the program. Those whose initial placements offered less independence reverted to about the level of utilization they had evidenced before admission to the program.

Level of activity of remaining patients. Table 3 summarizes the level of activity of the 50 remaining patients in six areas—mobility, self-care, vocation, socialization, housekeeping, and management of funds—and their correlations with one another. Most patients were fully mobile, could provide self-care, and were involved in a full range of socialization activities.

Thirty (60 percent) of the 50 original patients were employed, five competitively and 25 under a handicapped worker's certificate. Thirteen were employed as kitchen workers, eight as housekeepers, three as companions, three as laundry workers, one as a maid, and one as a groundskeeper. Almost three-fourths were able to perform at least moderate housekeeping duties. Only 19, or 38 percent, however, were able to manage their funds adequately.

Calculations of Spearman's rho for correlation between levels of activity in the six areas indicated that significant correlations existed between most activities except for the ability to manage funds, which correlated significantly only with housekeeping ability. Univariate regression analysis revealed that the only patient variable that correlated significantly with the sum of all activities was years of education ($r=.29$, $p<.05$).

Table 3
Performance of 50 original small group work therapy patients in six activities and correlations between activities

Activity	Patients N	Patients %	Correlated activities[1]
Mobility			Self-care, vocational status, socialization, housekeeping, managing funds
Full	49	98	
With assistance	1	2	
Self-care			Mobility, socialization, housekeeping
Self and room	45	90	
Self only	5	10	
With assistance	0	0	
Vocational status			Mobility, socialization, housekeeping
Competitive	5	10	
Handicapped worker	25	50	
None (pensioned)	20	40	
Socialization skills			Mobility, self-care, vocational status, housekeeping
Full range	41	82	
Moderate range	6	12	
Low range	3	6	
Housekeeping ability			Mobility, self-care, vocational status, socialization, managing funds
High	12	24	
Moderate	24	48	
Low	13	26	
None	1	2	
Ability to manage funds			Housekeeping
Yes	19	38	
No	31	62	

[1] $p<.05$, based on Spearman's rho correlations

Discussion

Several conclusions are apparent from our data. The original 130 patients in small group work therapy meet the criteria for chronic psychiatric patients (3). They represent a previously institutionalized subgroup of chronic patients that, on the average, is older, more passive, and generally more cooperative and compliant with treatment than the younger chronic patients described by Schwartz and Goldfinger (4). They are similar in many ways to the low-energy, low-demand patients discussed by Sheets and colleagues (22).

While in the work therapy program, patients were able to live in the community at a reasonable cost and to be dramatically less reliant on the hospital than they were before they entered the program. Without an independent control group, we cannot attribute this result to the effect of small group work therapy alone, although we know that most patients had been discharged on medications several times without success before being admitted to the program and that their hospital utilization increased significantly after leaving work therapy.

The average patient who left the program continued to use the hospital significantly less than he or she did before entering small group work therapy, suggesting that the pattern of institutional dependence had been broken. However, closer examination showed that the improvement was true only for patients who left small group work therapy for initial placements that offered more independence. Those whose initial placements offered less independence had the same rate of hospital utilization as they had before entering small group work therapy. Even these more difficult patients, however, were able to decrease their reliance on the hospital during their participation in the program.

It is important to remember that our study was derived from a clinical program for chronic patients and was not designed as a clinical trial. Hence findings are not the result of an experiment per se. Patients were not randomly selected for entry into small group work therapy, nor was a matched control group available for comparison. Nevertheless, it appears that of the original patients in the program, approximately one-third needed its support permanently, one-third were able to move on to less structured living arrangements, and one-quarter required even more support than was available in the program. This fact underscores the importance of a range of transitional and nontransitional community and institutional programs in any network of services for chronic patients (23,24).

It is also important to realize that patients who left small group work therapy for more independent placements were able to do so only after spending more than four years in the program. The process of community rehabilitation is a slow, arduous endeavor, and programs with artificial time limits on residential stay are inappropriate for many chronic patients (25).

Even though 26 percent of the patients ultimately left small group work therapy for less independent placements (Table 1), they were able to spend an average of 3.6 years in the program before that referral became necessary. Most returned to the state hospital because of an acute exacerbation of their psychiatric illness or the onset of a significant medical problem. The majority were eventually placed in nursing homes.

It appears that younger patients who had fewer hospitalizations and who had been married were more likely to leave the program for placement offering greater independence and that younger patients with more education stood the best chance of maintaining more independent living arrangements over extended periods. These findings are consistent with the current concepts regarding the prognosis of patients with schizophrenia (26).

As might be expected based on the natural histories of the major psychiatric illnesses (27), the longer a patient remained in small group work therapy, the greater the likelihood of his rehospitalization. No matter what the level of community support, some chronic patients will inevitably have exacerbations of their illnesses and require hospital treatment. However, a significant number of work therapy patients (52 percent) did not return to the hospital even after living for an extended period in the community. Available data, however, did not enable us to predict precisely which patients would eventually require rehospitalization.

Despite extensive institutionalization, most of the original patients still in the program on July 1, 1980, were capable of a full range of activities, and 60 percent were employed in a variety of jobs in the community. The significant correlations of vocational performance with socialization and with housekeeping ability indicate that emphasis on these activities in rehabilitation programs might be important in increasing patient employment.

Despite success in other areas, many patients continued to have difficulty managing their funds. Since budgeting is a relatively sophisticated task that many people without psychiatric histories find difficult, it should be no surprise that chronic patients also have problems in this area. This finding underscores the importance of teaching money management to chronic patients and suggests that some may require extended financial supervision even though they function well otherwise.

We believe there are several reasons for the success of the small group work therapy program. First, it was modeled after a program of proven effectiveness, the Fairweather Lodge. Fairweather and associates' principles (28) for social subsystems for chronic mental patients were carefully incorporated into the work therapy program to the extent possible.

Second, the program has always been staffed by dedicated and talented professionals. More important than their educational experience has been their willingness to improvise, to learn new treatment techniques, and to take personal and professional chances with patients whom others had labeled hopeless. Several current staff members have been with the program from the beginning, providing a level of continuity and familiarity seldom seen in programs for chronic patients. Bachrach considers such continuity essential for rehabilitation of chronic patients (29). In addition, the staff approach has been optimistic and expectant (30). While they have been readily available to provide support when needed, they have encouraged as much patient autonomy and group problem solving as possible.

Third, patients are screened for rehabilitation potential and compatibility. Although the original patients had been chronically institutionalized in Benton, they had demonstrated their ability to function well on the HIP unit prior to their transfer to small group work therapy community homes. Not only had they made individual progress, but also they had shown their willingness to work together as a group providing mutual support.

Individuals now known as young chronic patients (4,22), who characteristically exhibit severe behavior disorders, significant drug or alcohol abuse, repetitive criminal behavior, or sexual misconduct, were not referred to small group work therapy. Staff felt that these patients might stress the tolerance of the community too greatly and place the entire program in jeopardy. It remains to be seen whether a program like this one could be effective for the community treatment of this difficult subgroup of chronic patients.

Fourth, although the program has been independent and has had its own staff and budget, it has been closely linked to the state hospital. Original participants received extensive training on the HIP unit of Arkansas State Hospital prior to their transfer to the program, thereby easing their community adjustment. Initially the HIP unit and later the general wards of Arkansas State Hospital have readmitted patients from the program without delay, providing for rapid treatment of acute psychiatric or medical illness and the earliest feasible return to the community. Such hospital support has been crucial to the success of community programs for chronic patients (6). Knowing that back-up is readily available has made staff more willing to work with difficult patients. Close linkage between community programs and state hospitals has also conveyed to patients that hospitals can be used when needed but that their home is in the community.

Fifth, the program has been actively supported by community leaders. From the beginning, influential members of the community have agreed to serve on the small group work therapy corporate board. Their involvement has helped the program join the community with minimal resistance. They have also been a continued source of practical advice, especially about financial and legal aspects of the corporation that were beyond staff experience.

In summary, small group work therapy has been an effective community program of modest cost for selected chronic patients. Not only has it helped to keep previously institutionalized patients out of the hospital for extended periods of time, but it has also stimulated and supported their involvement in a variety of activities within the mainstream of the local community. Small group work therapy has provided a structure that reinforces a relatively independent life-style for chronic patients by emphasizing the importance of work and the ability to solve one's own problems whenever possible. It reconfirms the fact that with the proper guidance and support, many chronic patients can indeed be taught to lead constructive lives in the community.

References

1. President's Commission on Mental Health: Report to the President, vol 1. Washington, DC, US Government Printing Office, 1978
2. Talbott JA (ed): The Chronic Mental Patient. Washington, DC, American Psychiatric Association, 1978
3. Minkoff K: A map of chronic mental patients, in The Chronic Mental Patient. Edited by Talbott JA. Washington, DC, American Psychiatric Association, 1978
4. Schwartz SR, Goldfinger SM: The new chronic patient: clinical characteristics of an emerging subgroup. Hospital and Community Psychiatry 32:470–474, 1981
5. Stein LI (ed): Community Support Systems for the Long-Term Patient. New Directions for Mental Health Services, no 1, 1979
6. Bachrach LL: Overview: model programs for chronic mental patients. American Journal of Psychiatry 137:1023–1031, 1980
7. Cutler DL (ed): Effective Aftercare for the 1980s. New Directions for Mental Health Services, no 19, 1983
8. Braun P, Kochansky G, Shapiro R, et al: Overview: deinstitutionalization of psychiatric patients: a critical review of outcome studies. American Journal of Psychiatry 138:736–749, 1981
9. Test MA, Stein LI: Community treatment of the chronic psychiatric patient: research overview. Schizophrenia Bulletin 4:350–364, 1978
10. Carpenter MD: Residential placement for the chronic psychiatric patient: a review and evaluation of the literature. Schizophrenia Bulletin 4:384–398, 1978
11. Fairweather GW: Community Life for the Mentally Ill. Aldine, Chicago, 1969
12. Fairweather GW (ed): Social Psychology in Treating Mental Illness: An Experimental Approach. New York, Wiley, 1964
13. Fairweather GW: The development of group process in treatment with mental patients. New Directions for Mental Health Services, no 7:3–12, 1980
14. Fairweather GW: Implications of the lodge society. New Directions for Mental Health Services, no 7:89–97, 1980
15. Fairweather GW: Spreading the lodge society concept. New Directions for Mental Health Services, no 7:33–41, 1980
16. Fergus EO: Maintaining and advancing the lodge effort. New Directions for Mental Health Services, no 7:43–56, 1980
17. Larch BB: The lodge as an extension of the hospital. New Directions for Mental Health Services, no 7:59–65, 1980
18. Safier D, Barnum R: Patient rehabilitation through hospital work under fair labor standards. Hospital and Community Psychiatry 26:299–302, 1975
19. Sandall H, Hawley TT, Gordon GC: The St. Louis community homes program: graduated support for long-term care. American Journal of Psychiatry 132:617–622, 1975
20. Hyde J: Survival analysis with incomplete observations, in Biostatistics Casebook. Edited by Miller RG. New York, Wiley, 1980
21. Vital Statistics of the United States, 1975, vol 2, part B: Mortality. Hyattsville, Md, National Center for Health Statistics, 1977
22. Sheets JL, Prevost JA, Reihman J: Young adult chronic patients: three hypothesized subgroups. Hospital and Community Psychiatry 33:197–203, 1982
23. Bachrach LL: A conceptual approach to deinstitutionalization. Hospital and Community Psychiatry 29:573–578, 1978
24. Faulkner LR, Terrwilliger WB, Cutler DL: Productive activities of the chronic patient. Community Mental Health Journal 20:109–122, 1984
25. Peterson R: What are the needs of chronic mental patients, in The Chronic Mental Patient. Edited by Talbott JA. Washington, DC, American Psychiatric Association, 1978
26. Lehmann HE: Schizophrenia: clinical features, in Comprehensive Textbook of Psychiatry, 3rd ed. Edited by Freedman AM, Kaplan HI, Sadock BJ. Baltimore, Williams & Wilkins, 1980
27. Diagnostic and Statistical Manual of Mental Disorders, 3rd ed. Washington, DC, American Psychiatric Association, 1980
28. Fairweather GW (ed): The prototype lodge society: instituting group process principles. New Directions for Mental Health Services, no 7:13–32, 1980
29. Bachrach LL: Continuity of care for chronic mental patients: a conceptual analysis. American Journal of Psychiatry 138:1449–1456, 1981
30. Test MA, Stein LI: Practical guidelines for the community treatment of markedly impaired patients. Community Mental Health Journal 12:72–82, 1976

The small-group technique designed by Fairweather and his colleagues, when utilized as a nursing procedure, was staggering in its implications; it would change the chronic patients' nursing care from staff help to self-help in one operation.

The Lodge as an Extension of the Hospital

Billie B. Larch

As late as 1963, the Benton unit of the Arkansas State Hospital, now Benton Mental Health Services, was truly a legend. For many years, patients who did not respond to conventional treatment methods were transferred from the Little Rock Hospital to become victims of backward practices at Benton. This was primarily due to lack of sufficient funds to employ adequate numbers of trained personnel to carry out an effective treatment program. And since most of the available treatment methods had been used without success, custodial care became the normative method of caring for the mentally ill. This, of course, led to chronic institutionalization. Patient attitudes toward the hospital were probably best expressed by the feeling that a transfer to Benton was the end of the road. This feeling was shared by family, friends, and personnel alike. Years of total regimentation had caused some patients to deteriorate into a completely withdrawn state.

Even attempts at change were often not successful. During 1963, for example, a project of the Arkansas Rehabilitation Services, Department of Health, Education, and Welfare, Vocational Rehabilitation Administration (Grant No. RD 784) demonstrated that many patients were unable to adjust to new community settings that required more responsibility from them and had to be returned to the well-regimented wards in which they had been accustomed to living. But not all members of the hospital staff had completely given up hope. Some felt that given a facility to fill the void between the back ward and complete rehabilitation—a program in which a therapeutic environment could be created for the patient—the personnel could be motivated to develop anew the attitude that there was hope for the chronically mentally ill.

In an attempt to activate this hope, an application was submitted to the National Institute of Mental Health for a grant to provide additional professional staff to plan and carry out an intensive, comprehensive treatment program that would demonstrate that chronic institutionalized patients could be rehabilitated. The grant was approved 1 June 1964, and the hospital improvement project became a reality.

During the first year of operation, a discharge rate of 22 percent was achieved. This was a result of the combined efforts of all staff members utilizing conventional methods in carrying out a carefully planned, individually oriented, treatment program. While the improved discharge rate was encouraging, the staff had the general feeling that if some new techniques could be discovered that would return these patients to the community in groups, the rate could be increased. Few of these patients had families or friends who could offer either moral or monetary support, a factor that often precipitated the patient's return to the hospital. A search through the literature for such a technique revealed a new book, *Social Psychology in Treatment of Mental Illness: An Experimental Approach,* written by George W. Fairweather. A research team in Palo Alto, California, where Fairweather was located at that time, had demonstrated experimentally that a social system of patient task groups releases patients to the community at a significantly faster rate than patients from a traditional hospital treatment program.

Dr. Fairweather's book was read and studied carefully by each staff member to determine if this new group technique could be utilized for the long-term chronic patient population at the Benton hospital. We decided that it could be if changes were made in the conduct of the ongoing program. Of these method changes, the greatest and perhaps most difficult change—the omission of T.L.C. (Tender Loving Care) as the central factor in the program—would have to come in the nursing procedure. Tender Loving Care was defined as "the patient is sick and we as nurses take care of him or her." It had been for many years not only an accepted method, but the central part of almost every nursing care plan. It seemed difficult to imagine administering nursing care without it, and even though in recent years there had been certain modifications, for the most part patient-staff procedures had remained essentially unchanged.

The new small-group technique designed by Fairweather and his colleagues (1964), if utilized as a nursing procedure, would change the chronic patients' nursing care from staff help to self-help in one operation. What this meant was rather staggering: Staff would treat patients as responsible persons in the framework of their own reference group. The group itself would correct or compensate for its members' inappropriate behavior. Certainly this was a change in thinking and approach, and it presented a great challenge.

To make matters more complicated, the method of communication between the institutional patient and nurse, according to small-group principles, had to be highly impersonal. As recommended in the book, a system was devised for the staff and patients to communicate with each other by written notes. Requests of a routine nature, such as weekend trips, trips into town, and appointments with various staff members, were handled in this manner. However, physical complaints or emergencies were handled in the usual, conventional manner. Rules and regulations written by the patients and staff were used, initially, until new norms developed. A structured situation was set up with a schedule allowing very little free time. All ward assignments were written in great detail. Groups were formed and schedules were given to the group members.

The group development plan assigned each patient to a task group. In order to leave the hospital, each patient had to go through four levels of performance with the responsibilities and privileges commensurate with the patient's level of adjustment. But the group as a unit was responsible for each and every member. The group would meet four of the five working days each week without a staff member being present. At these meetings the group members evaluated each other and prepared recommendations for step level promotions that were then presented to the staff on the fifth day. Evaluations were presented verbally and/or in writing. Notes pertaining to ward regulation infractions, future plans, and morale and functioning of the group were also evaluated in terms of the group's decisions about how such concerns would be handled.

Following the group's presentation of recommendations to the staff, the staff met privately to consider the recommendations. The primary staff consideration was how well the group was taking its responsibility for each member and the reality of its recommendations. Thus the staff's job was training the group to become cohesive and to solve its members' problems.

These were some of the central features of the small-group program presented in the Fairweather book. We thought that the program might work at Benton.

In an attempt to activate the program, Fairweather was contacted for advice. He suggested that David H. Sanders, a research colleague, might be able to aid our hospital in creating the small-group program. At this time, we learned that these small groups had been moved in Palo Alto into a community lodge. This seemed all the more interesting.

Thus Sanders, one of Fairweather's associates, visited the project to orient the staff, assist with setting up the program, and discuss potential emergent problems. It probably should be mentioned here that he also imparted his enthusiasm to the staff members, who like the original staff at Palo Alto were having difficulty in accepting the change from traditional treatment techniques. Two modifications were deemed necessary due to cultural and economic differences from the Palo Alto Lodge. First, no personal funds were available for a monetary reward system (some VA patients had funds available from pensions, while most of these patients had very little, if any, resources that could be utilized). Second, all VA patients had been males. Here patients were of both sexes and this would entail the formation of female groups with appropriate work assignments. Also, it should be noted that the mean length of hospitalization of the Palo Alto group had been less than five years, while the mean of the Benton patients was 13.7 years of hospitalization. At Sanders' suggestion the National Institute of Mental Health (NIMH) was contacted and agreed to set up a monetary sum to provide a small but adequate reward system. The following four months were then used by the staff to establish routines and rules that would be necessary to carry out the program.

Four task groups composed of fifteen members each were formed. The remaining twelve patients, mostly diagnosed as catatonics, were considered too severely regressed to function and were assigned for conventional intensive treatment until they improved sufficiently to be placed in a group. The groups were oriented to the program, given schedules and assignments, and told that the group was responsible for each member. Leadership was probably the first norm established within the group; to the staff's amazement and disbelief it evolved the first day. Another seemingly very strange thing happened. Each patient carried out his or her ward duties and left the ward for work assignment areas from the very first day, even most of the patients who had received total help for many many years. We had read the book and we believed it would work but actually to see it was fantastic and we felt it could not last. Nevertheless, in the following six months, we continued to adapt the Fairweather method to our situation and, I may say, continued to marvel at the results. It was anticipated at the beginning that forty of the sixty patients would be able to leave the hospital within a year and that 30 percent would have to be retained in the hospital for a longer period of time, possibly in new groups that would be formed. At this point, six months after beginning the small-group treatment technique, the predicted forty patients were ready to leave the hospital and return to the community—six months earlier than had been anticipated. Some of the patients began a training period during which they worked in the community and returned to the hospital each night. This situation existed only a short time until family type quarters were set up. The day-to-day effects of group process had produced many changes within the reference group. And perhaps of equal importance, the same group processes—the establishment of norms and values, a common goal toward which the group must work and so on—have provided incentive, motivation, and cohesiveness among the nursing personnel and, as a result, must be considered a factor in the success of this technique. The staff group seemed to have evolved at approximately the same speed as the patients' group, into a cohesive, problem-oriented group working around the clock. This situation had seldom existed here on a ward in the past; the small group techniques that were originally research oriented and aimed at returning chronic patients to the community also provided a pattern of ward management, one that was therapeutic in every sense of the word.

Inevitably the path from the hospital led to the community. The placement of groups in boarding houses was contemplated but found to be impractical because none of the local boarding houses would accept groups of mental patients. The staff attempted to educated the public but soon learned that this would take a prolonged period of time, while, at the same time, holding back the groups, who were ready to move into the community. The idea of a halfway house, with perhaps a retired couple for supervision, was dropped in favor of the autonomous Lodge plan. To accomplish this, the staff decided to allow the group to use room and board money provided for them by Vocational Rehabilitation to rent a furnished house, set up housekeeping at the unit, and assume the responsibility of taking care of its needs.

Needless to say, when the first groups were placed in the community the staff had many fears. These fortunately proved groundless. Two psychiatric technicians who had been on the project since its beginning were selected to work with the group members in the community. These technicians were referred to as community coordinators and acted as a liaison between the members, employer, and the project staff. The selection of these individuals was given careful consideration because it was believed that the success or failure of the program depended on them and their relationship with the group members. Since the supportive actions of the community coordinator were the last link with the hospital, whether the group members could adjust in the community setting depended to a large extent on how well the coordinator performed her or his job. Problems of adjustment, shopping for groceries and clothing, guidance and counseling in everyday personal affairs were among the coordinator's duties. In addition, physical complaints were relayed to the staff psychiatrist for evaluation and, if necessary, members were returned on an outpatient basis for treatment. Gradually the group assumed full responsibility for its functioning, thus freeing the coordinator to work with new groups in the community.

Work contracts were made with employers before the group left the hospital, and a written confirmation or oral agreement was made to accept a group for training with the stipulation that if the group worked effectively the employer would place them on the payroll at the end of that period. The employer actually was contracting for a service that was much more acceptable to him or her than a formal employee-employer relationship: Group work was carried over into the work situation because the entire group worked in the same business establishment or institution, although not everyone did the same job. What job a member did depended upon his or her work potential. Since an employer would rather pay for a service than have an employer-employee relationship, a new entity had to be formed, the Benton Hospital Sheltered Workshop Improvement Corporation, a nonprofit, tax exempt corporation.

Today the corporation is entitled Small-Group Work Therapy Incorporated. The original directors of the corporation were the psychiatrist, social worker, psychologist, and nursing director from the project. Three members of the staff were from vocational rehabilitation services and two from the county mental health association where the groups worked. It was this corporation that made work agreements with employers, collected the money for services, and turned it over to the group after income tax deductions had been made. It was also the corporation's duty to make certain that none of the group members were exploited and that all wage and hour regulations were met. While, from a legal perspective, all the money in the corporation belonged to the group members, it was still anticipated that several philanthropists would make sizable contributions before the year was over. These contributions were to be used to tide the members over should periods of unemployment arise.

Places of employment were hotels, country clubs, golf courses, and nursing homes. Even though the first groups were rather difficult to place, there were soon more requests than there were available groups. The shortage did not indicate a shortage of patients themselves but a time factor. At that early date, it took approximately one year to prepare patients for community living. The time factor changed as the staff became more proficient in group methods and, accordingly, the time needed to prepare groups to move into the community decreased.

During the past fifteen years, approximately 550 people have moved out of the hospital into the community. Many of them have moved on to their own homes, gotten married, or are living alone, Even so, they continue to act as a group. The group structure remains the same in the homes, but the places of employment vary at this time. Members no longer all work as a group at any facility or institution, and places of employment are very much as they were in the beginning with the change that other places of employment have been found. The place of employment varies with the potential of the individual. The Board members of the program are now business and professional people in the community. One of the local banks handles all the accounts for the patients. There are general (group) accounts and there are individual accounts for each member. No member is allowed to live off the work of other members. Each must make his or her own contribution to the expense of the home and take care of his or her own expenses.

Basically, the failures we have had in the past fifteen years have been those patients who have not had training in group process within the hospital. There are approximately 100 people still living in the community group program they first went into some fourteen years ago. These people have either not been able to leave the group or have not desired to do so, but all have been able to function as members of a small society.

Professional group leadership has changed over the years even though a few of the original leaders still work in the community. The psychiatrist who initiated the program in the hospital in 1965 is still actively involved in its function. The community coordinator is now program coordinator in the community. The nursing director is no longer employed by the hospital but is a consultant to the groups.

One of the problems in the beginning was finding housing for the groups, but this is no longer so. Landlords in the community now approach the program coordinator in order to rent her other houses. None of the homes have been bought or purchased by groups. One of the greatest problems still remains educating the public. Whereas most people in the community know the expatients are there and accept them as people, the idea of mental patients moving next door is still not readily accepted. It seems very clear that community reaction toward ex-mental patients should be of deep concern to all mental health workers.

References

Fairweather, G. W. (Ed.). *Social Psychology in Treating Mental Illness: An Experimental Approach.* New York: Wiley, 1964. (Now available from University Microfilms International, 300 N. Zeeb Road, Ann Arbor, MI 48106, Order No. OP 50191.)

Billie B. Larch was a member of the original team that established the first Lodge replicate. She is currently associate chief of Nursing Education at the Veterans Administration Hospital in Little Rock, Arkansas. She is also consultant to the Arkansas Mental Health Services and past president of the Coalition for Community Living. She received her master's degree in Nursing from the University of Central Arkansas in 1971. Billie Larch has also received the Linda Richards award from the National League of Nursing in 1969 for her work with the Lodge Society.

This paper was presented
at the 31st annual meeting
of the International
Society of General Systems
Research Organization.

REDESIGNING NURSING HOMES

Patricia M. Trussell and Billie B. Larch

Abstract

Nursing homes in the United States are health care institutions "of last resort" for many human beings. Nursing homes straddle two major kinds of societal systems; home and health care. This results in their being poor relation to both in terms of meeting the social and the health care needs of their residents. This paper examines the idea of redesigning nursing homes as homes primarily - not health care institutions. The success of hospitals in recent decades has contributed to nursing homes developing as health care institutions rather than in other ways. Yet the social diversity of many nursing home residents as compared with the primary medical needs of hospitalized patients has been overshadowed by the nursing home as a health care institution. The proposal is to redesign nursing homes to meet broader social objectives than dependent custodial care. This would result in fewer nursing home beds, more day care centers, residential living groups, supportive home health care services among others. Two specific examples are presented; one implemented by a nurse in Arkansas, the other by a national union. In Arkansas in 1964 the second author of this paper, working wh officials at a state mental institution, implemented the establishment of residential living for selected mental patients. This program, in existence for 23 years, now includes nursing home residents. The second example concerns the pilot program initiated in 1987 by the United Auto Workers of America, in which their contract with the Ford Motor Company and General Motors Corporation include home care services to "maintain a person's independence as long as possible". These programs differentiate between persons whose primary needs are other than medical and nursing and those whose primary needs are medical and nursing. The latter would be cared for in institutions limited to these patients and/or in special wings of general hospitals (as is done in some places now). The benefits of redesigning nursing homes are concurrently increased quality of care and decreased costs.

Introduction

Do nursing homes have to be "catch all" institutions "of last resort"? Can they be redesigned to better meet the humanitarian and economic realities of their residents? These authors believe they can and indicate ways to do it.

Family - a primary social system

A family is the primary human social system into which persons are born and raised, then marry and create families of their own and the cycle is ongoing. It has been this way through eons of time, different societies and various cultures.

It is through family that everyday living happens in close personal relationships entwining the provision of food, clothing, shelter and safety for family members. It is through family that perspons learn and develop patterns of dependence, independence and interdependence. At birth a baby is completely dependent, gradually acquiring independence with walking, talking and growing up, then learning interdependence through cooperative family living.

It is with family that people share significant happy life events such as birth, graduation, marriage, Christmas and Thanksgiving. it is also family that support each other at life's crises, such as illness, operations, divorce, accident and death.

Some say that family in today's society is disintegrating; but that is not the view of others. The emphasis in the Spring, 1977, issue of Daedalus titled "The Family" is that family has been and is a strong and lasting institution.

Other social systems

But the family does not do it all. Over time and in different ways other social systems have developed to carry out specific functions for groups of families such as tribes, clans and nationalities. A system of government has the function of overall protection and rule. A system of agriculture has the function of growing food and distributing it. In the United States in the past 150 years a system of public education has developed to teach children, who are required to attend.

Health Care Systems

In more recent times in the United States a complex system of providing health care has developed apart from the family. One specific purpose of health care is to diagnose and treat diseases of human beings in the context of today's medical knowledge, powerful drugs and technologically sophisticated equipment. These activities take place primarily in doctors' offices, ambulatory facilities and hospitals.

Today, unlike 50 years ago, middle aged persons with broken hips, heart attacks, diseased gallbladders, pneumonia and the like, rapidly recover after a few days in a general hospital. Persons with mental illnesses, who 50 years ago spent the rest of their lives in a mental institution, can now be treated with medications that enable them to live outside a mental institution. Persons with tuberculosis, who 50 years ago died young from the disease or spent months in a sanitarium, are now treated with medications and carry on their ususal lives.

It is noted that only by a physician's order is a patient admitted to a hospital, in the past to a sanitarium, and in most cases to a mental hospital. Medical education in the United States is designed to teach the diagnosis, treatment and followup of disease.

Though hospitals per se have a long history and have existed in different cultures since the days of the Greeks, today's hospitals in the United States are "live in" institutions that focus on patients' medical problems, their diagnosis, treatment and followup. Human needs of food, shelter and safety are provided in the context of the existing medical problems by a variety of highly trained workers: e.g. physicians, nurses, dietitians, social workers, physical therapists, surgical technicians, respiratory therapists, and so on.

Modern hospitals have been very successful institutions in doing their particular functions. In fact, the point can be made that the good work of physicians and hospitals in recent decades have contributed to more people living longer, to die at an older age of some other cause.

It is also true that in hospitals today, socially, patients are in a very dependent relationship. they wear hospital gowns, bathrobes and slippers, hardly the attire of independent adults. They can be up and about only by a physician's order, which includes "BRP" (bathroom privileges). In a hospital it is a privilege to be able to go to the bathroom! Patients' diets are ordered by the physician and served according to a hospital schedule.

However, since most hospitalized patients feel sick and their stay is short, they tolerate the dependence role. At discharge, they dress in their own clothes and go home. In reality patients go to a hospital willingly to have a baby or for an acute illness, stay a few days and go home to resume independent and interdependent living.

Nursing homes are different

That is not the way it is in nursing homes, another kind of "live-in" health care institution in the United States. Patients do not go to nursing homes willingly; in fact, they are usually reluctant to go. In nursing homes, patients tend to stay long periods of time. They receive little nursing. Nor is the institution a home!

Nor is it a junior hospital! However, to walk down the corridor of a nursing home to the nurses' station would remind one of a hospital. Hospital beds are the predominant object in each patient room. Alongside each bed is a bedside stand as in a hospital. Attached to each bed are bedside rails and a call button, as in a hospital. Close by each bed is a chair.

The nurses' station in both hospitals and nursing homes is an area "off limits" to patients. Locked medicine cabinets, chart racks, weight scales, medical records, paper forms and a clock are what one see at nursing stations, be they in hospitals or nursing homes.

Like a hospital, admission to a nursing home is only by a physician's order and a medical diagnosis. Sometimes the medical diagnosis is merely a tag to enable admission.

Unlike a hospital, for which admission is specific to a medical problem, underlying reasons for admission to a nursing home are as often social in nature as they are medical. Persons are admitted to nursing homes because they have no family, no home, no economic resources and no place to go. It is a "last resort". (Kane and Kane, 1978:914) Other persons are admitted to nursing homes who do have families but can't get along with them or there is a history of family abuse. Still others are dependent persons with a long history of chronic mental illness who require daily medication and a nursing home is the best assurance they will receive it.

Still others are older, confused persons who cannot be left alone, yet adult family members are all employed outside the home. Persons with severe dementia are admitted to nursing homes because they require more personal care than a family can provide.

Also, younger persons are admitted to nursing homes. Bad accidents and neurological illnesses often result in a younger person no longer being able to live alone and care for oneself. Then, there are the adult mentally retarded persons in their 30s and 40s who have been cared for at home by parents who have recently died and the mentally retarded persons have no place else to go. This also happens with persons born with cerebral palsy and other neurological conditions.

Nursing homes admit terminally ill persons slowly dying with a malignancy and whose economic resources have been used up with previous therapy. More recently, nursing homes admit another group of patients from hospitals - those with short term intensive nursing and rehabilitative needs and who are expected to recover. Hospital payment for Medicare patients is now prospectively determined by Diagnostically Related Categories (DRCs). Selective patients under Medicare and in need of skilled nursing and/or rehabilitative services are being discharged to nursing homes for specified time periods.

Thus, nursing homes in the United States have become a "catch all" health care institution "of last resort".

Because they are considered health care institutions, they are organized to emphasize medical and nursing activities. These include medications, their ordering, storing, administering and recording; medical records, i.e. written records of patients' conditions, medications received, treatments given and behavior noted and recorded at least once every eight hours; the taking of vital signs and their recording; bathing patients, helping them into wheelchairs or stationery chairs, taking them to the bathroom, keeping incontinents clean and dry, and other tasks of personal care to dependent people.

Like in hospitals, the organization of nursing homes fosters dependence and provides little opportunity for patients to act independently or interdependently. Activities of daily living, e.g. getting up; eating, bathing, sleeping, are on a schedule. Wanting to do something at another time is a "no no". Leaving the nursing home without signing a permission is another "no no". Patients, or residents as they are often called, are expected to "fit in" and not ask for deviation from the schedule, like a 6 A.M. cup of coffee if one is an early riser. Thus persons, who a few years earlier in their lives were independent and living satisfactorily, are forced to return to dependent behavior patterns. No wonder many of them don't like it.

As in hospitals the cost of care increases despite efforts to contain it. Reasons for this are complex and will not be discussed in this paper. Closer scrutiny than in the past may show that the function of nursing homes for many residents is more social than medical and that nursing homes should be redesigned, not as a "catch all" and "last resort" institution. They should be redesigned to serve a specifically defined group of patients. In some communities this is beginning to happen. A variety of different services are being developed that provide greater use of the independent and interdependent strengths of family. The Hospice movement is one. Another is the development of day care centers for persons unable to stay alone in the daytime and whose adult family members are employed outside the home. Home health nursing, home maker and physical therapy services have more potential than at present. Experienced registered nurses practicing autonomously as nurses can be helpful to families. Residential living for small groups of persons unrelated by kinship to each other is another possibility. Two examples, one in existence since 1964 and the other a 1987 pilot experiment follow.

Residential small group living

In 1964 one of these authors was employed as a nurse in the State Mental Hospital System of Arkansas. This was at a time when yearly admission to mental hospitals was increasing, hospitalization was for years and often until death. Hence, mental hospitals had an increasing population. Patients became institutionalized and very dependent. Books like The Snake Pit called public attention to the situation.

In 1964-65 the officials of the State Mental Hospital System in Arkansas evaluated the situation. A major difference was found to exist between persons institutionalized a long time and persons with mental illness who had been cared for at home. That difference was the completely dependent behavior of institutionalized persons, who had no rights and made no decision regarding their lives.

Staff of the Arkansas State Mental Hospital searched the literature and found relevant and experimental work being carried out by George Fairweather, a social psychologist, then at a V. A. Hospital in Maryland. He wondered if selected V. A. patients could remain longer in the community if steps toward independent living were available and the patients were willing to try.

Beginning in a small way in Maryland, Fairweather demonstrated that this concept was realistic and effective. Later Fairweather demonstrated it on a much larger scale at Palo Alto, California. His ideas have spread to 17 other states and Canada.

But in 1964-65 they were just beginning when they made sense to the staff at the State Mental Hospital in Arkansas. A project was initiated under the direction of a nurse with a Master's degree, who is the second author of this paper.

She realized the value of the concept and that it would require modifications in Arkansas, one of which was that groups would be comprised of women, whereas Fairweather's work at that time focussed on male veteran patients.

Selected patients of the same sex and varying ages but all with psychiatric diagnoses were to live as small families without live-in staff. They were responsible for each other and their own well being in terms of activities of adult living. Persons who earlier in their lives had lived independently and interdepently now had the opportunity to try to do so again.

Over the past 22 years more than 1,000 persons have benefitted from the program. Today, program participants include not only state mental hospital patients, but selected nursing home patients. Referrals are made by physicians and social workers in the community who have seen the benefits of the program.

One benefit, not heretofore mentioned, is economic. The cost of nursing home care, built as it is on the hospital model, continues to increase in a disproportionate manner. That is to say, the cost of care of those in nursing homes who represent approximately 5% of those over 65 years of age takes a large amount of the Medicaid funds in every state. Following is an experimental program designed to reduce the cost of care.

A Pilot Union Contract

The November 2, 1987, issue of The New York Times reported that the new contracts of the United Auto Workers with both Ford Motor Company and General Motors Corporation include a pilot program to pay for services for at home for severely impaired employees and/or retirees. William Hoffman, head of the UAW's benefits department, stated, "The emphasis is to maintain the person's independence as long as possible". The new program "will assist the severly impaired in performing what, for them, are difficult activities of daily living, such as eating, bathing, toileting, homemaker chores, transportation".

It is reported that UAW officials believe the program can become a model for other employers and even influence public policy. Hence, from two different perspectives, humanitarian and economic, there are beginning efforts to redesign nursing homes.

Benefits of Redesigned Nursing Homes

Benefits of redesigned nursing homes as family adjuncts can accrue to both patients and the economy. If the overall objective of redesigned nursing homes is to build on and reinforce independent and interdependent living patterns that served persons well in younger years, not only will the quality of their living be improved, but also at less cost.

If nursing homes continue primarily as health care institutions in which patients' dependence is a dominant behavior pattern, the cost of operating such homes is bound to increase. The need for Medicaid funds will increase. This, in turn, can increase taxes and foster conflict between taxpayers living on fixed incomes trying to maintain their independence and those in nursing homes completely dependent on others.

There is need for institutions whose primary purpose is long term and medical and nursing oriented. But for many of today's nursing home residents, the need is for organizations and agencies that build on family strengths and promote independence and interdependence. This calls for redesigning present day nursing homes.

References

Fairweather, G.W. (Ed) (1964). Social psychology in treating mental illness: an experimental approach. New York: John Wiley and Sons.

Fairweather, G.W., Sanders, D.H., Maynard, H., & Cressler, D.L. (1969). Community life for the mentally ill: an alternative to institutional care. Chicago: Aldine Publishing Company.

Fairweather, G.W., Sanders, D.H. & Tornatsky, L.G. (1974). Creating change in mental health organizations. New York: Pergamon Press.

Fairweather, G.W. (Ed) (1980). The Fairweather lodge society: a twenty-five year retrospective of treatment innovation and dissemination research. New Directions for Mental Health Services. San Francisco: Jossey-Bass, Inc.

Faulkner, L.R., McFarland, B.H., Larch, B.B., & Yohe, C.D. (1986). Small group work therapy for the chronically mentally ill. Hospital and Community Psychiatry. 37:3 273-278.

Freudenheim, M. (1987, November 2). G.M. and Ford pacts provide custodial care. The New York Times. p 25.

Kane, R.L., & R.A.Kane (1978). Care of the aged: old problems in need of new solutions. Science. 200:4344 913-919.

Larch, B.B. (1980). The Lodge as an extension of the hospital. In G.W. Fairweather (Ed) New Directions for Mental Health Services: a twenty-five year retrospective. San Francisco: Jossey-Bass, Inc.

Graubard, S.R. (Ed) (1977). The family (Special issue). Daedalus. 106:2.

Ward, M.J. (1946). The Snake Pit. New York: Random House.

UNDERLYING REASONS FOR ADMISSION

HOSPITAL	NURSING HOME
1. DIAGNOSIS AND TREATMENT OF MEDICAL PROBLEMS OF INDIVIDUALS	1. OLD AGE AND NO ONE TO TAKE CARE OF HIM/HER
	2. MENTALLY ILL, DISCHARGED FROM MENTAL HOSPITAL AND HAS NO ONE TO SEE THAT MEDICINES ARE TAKEN
	3. CAN'T GET ALONG WITH FAMILY
	4. MENTALLY RETARDED AND PARENT(S) HAVE DIED
	5. SUFFERED ACCIDENT OR SURGERY AND HAS LOST MANY PHYSICAL AND/OR MENTAL CAPABILITIES
	6. ADULT RELATIVES WORK OUTSIDE THE HOME; SO NO ONE IS AT HOME DURING THE DAY
	7. HAS SEVERE DEMENTIA
	8. IS TERMINAL WITH A MALIGNANCY
	9. HAS SEVERE DIABETES, REQUIRING DAILY INSULIN INJECTIONS; LIVES ALONE AND CANNOT SEE TO SELF-ADMINISTER INSULIN OR PREPARE FOOD
	10. HAS HAD STROKE WITH RESIDUAL AFFECTING MOBILITY
	11. CHRONIC, DEBILITATING NEUROLOGICAL DISORDERS

SIMILARITIES BETWEEN TODAY'S HOSPITALS AND NURSING HOMES

1. ADMISSION IS BY A PHYSICIAN'S ORDER AND MEDICAL DIAGNOSIS
2. SIMILIAR IN PHYSICAL DESIGN
3. HIGHLY ROUTINIZED DAILY ACTIVITIES
4. FOCUS ON CARRYING OUT PHYSICIANS' ORDERS
5. MANY MEDICATIONS ADMINISTERED
6. COST OF CARE CONTINUES TO INCREASE
7. DEPENDENT ROLE OF PERSON ADMITTED

DIFFERENCES BETWEEN TODAY'S HOSPITALS AND NURSING HOMES

HOSPITAL		NURSING HOME
SHORT	LENGTH OF STAY	LONG
YES	WILLINGNESS TO BE ADMITTED	NO
HIGHLY SKILLED	PERSONNEL	MINIMAL
NON PROFIT AND PROFIT MAKING CORPORATIONS	LEGAL ENTITY	PROFIT MAKING CORPORATIONS OR BUSINESS
MEDICAL	UNDERLYING REASON FOR ADMISSION	SOCIAL

SO WHAT ?

- REDESIGN NURSING HOMES SO THAT THEY FOSTER INDEPENDENT/INTERDEPENDENT LIVING
- PUBLIC AWARENESS IS MOVING IN THAT DIRECTION - GIVE UNION EXAMPLE
- THE CO-AUTHOR OF THIS PAPER HAS HAD 22 YEARS EXPERIENCE IN ARKANSAS WITH ONE ALTERNATIVE

FAIRWEATHER'S UNDERLYING PREMISE

INTERDEPENDENT GROUP LIVING AS A "FAMILY" IN THE COMMUNITY CAN SUPPLANT INSTITUTIONAL LIVING FOR SELECTED PERSONS

WHAT HAS HAPPENED IN ARKANSAS DURING PAST 22 YEARS

- OVER 1000 PERSONS HAVE BENEFITED
- HAS BEEN CONTINUOUS FOR OVER 22 YEARS
- M.D.'S AND SOCIAL WORKERS IN THE COMMUNITY NOW REFER PERSONS TO THE PROGRAM AS AN ALTERNATIVE TO A NURSING HOME
- NO FEELING OF BEING IN AN " INSTITUTION OF LAST RESORT"
- QUALITY OF LIVING OF GROUP MEMBERS HAS BEEN ENHANCED
- GROUPS MAKE THE DECISIONS ABOUT DAILY LIVING

REDESIGNED INSTITUTIONS/ AGENCIES/SERVICES

TO INCLUDE

- HOSPICE PROGRAMS
- GROUP LIVING HOMES
- DAY CARE FACILITIES
- OPPORTUNITY TO LEARN SALEABLE SKILLS
- NURSING HOMES LIMITED ONLY FOR PERSONS WITH SEVERE DEMENTIA
- INSTITUTIONS SPECIFIC TO TERMINALLY ILL WITH NO FAMILY
- INSTITUTIONS SPECIFIC TO SEVERELY MENTALLY ILL WHO HAVE OUTLIVED FAMILY
- HOME CARE SERVICES

COMPARISON OF BEHAVIORS OF PRESENT NURSING HOME RESIDENTS AND GROUP LIVING RESIDENTS

NURSING HOME DEPENDENT	GROUP LIVING INDEPENDENT/INTERDEPENDENT
1. ACTIVITIES OF DAILY LIVING CONTROLLED BY INSTITUTION	1. RESIDENTS SET UP SCHEDULES OF DAILY LIVING
2. NO CHOICE OF LIVING ARRANGEMENTS	2. CHOICE OF LIVING ARRANGEMENT
3. RECREATIONAL ACTIVITIES PLANNED BY OTHERS	3. PLAN OWN RECREATIONAL ACTIVITIES
4. NO "VACATIONS"	4. CAN MAKE VACATION PLANS IF SO DESIRED
5. RARELY SEEN BY PHYSICIAN	5. CAN GO TO PHYSICIAN'S OFFICE AS DESIRED
6. CANNOT LEAVE AT WILL	6. CAN LEAVE AT WILL OR TO VISIT WITHOUT WRITTEN PERMISSION
7. COSTLY	7. LESS COSTLY
8. LOSS OF FEELING OF SELF-ESTEEM AND SELF-WORTH	8. MAINTAINS SELF-ESTEEM, AND FEELINGS OF SELF-WORTH - MAY EVEN FEEL SELF-ACTUALIZATION

SMALL GROUP WORK THERAPY, INC.
FACT SHEET

The Small Group Work Therapy, Inc. program was designed and implemented in 1965 for patients who had been residing for at least five (5) years at the Benton State Hospital. The program was the first developed in the nation adopting concepts and principles of Dr. George Fairweather and Associates which included the need for a supportive and productive social sub-system while encouraging as much autonomy and individual functioning as possible. Fairweather Lodges are now in 13 states.

The program has a non-profit corporation, Small Group Work Therapy, Inc., which is responsible for program money management, development of work contracts, and distribution of group member funds.

Over 900 individuals have been through the program, and, in most cases, have advanced to a more autonomous level of living. At the present time there are 62 individuals comprising 5 female and 3 male groups living in well-maintained, attractive houses. The corporation now owns 3 of those houses.

Initially, a strong work element was a component of the program. At the present time the group member average age has risen to 56 and many individuals are retired. At this point 15 of the 62 group members are employed in the community.

PROGRAM FEATURES

*	GROUP GOVERNMENT	Each home has a leader who presides at regular meetings to assess individual and group needs and solve problems.
*	HOUSING	Group members maintain their own homes and share expenses.
*	PERSONAL RESPONSIBILITIES	Each group member is responsible for obtaining and caring for clothing and personal expenses (cosmetics, medical expenses, etc.).
*	CASE MANAGEMENT AND MEDICAL SERVICES	The Division of Mental Health provides administrative services and employs 4 LPTNs, a consulting R.N. and psychiatrist. If the group is unable to resolve problems or an emergency arises, staff are called at home.
*	EMPLOYMENT	Employment opportunities are available in the community.
*	COST	$300.00 per month.

AARP- FALLING DOWN ON JOB.
WHAT ABOUT MEMBERS WHO ARE 80 AND ABOVE? ARE THEY NOT ENTITLED TO INSURANCE PROTECTION? WHY LET THE INSURANCE COMPANY WHO WRITES THE PLAN DISCRIMINATE AGAINST MEMBERS 80 AND ABOVE?

Item 15

THE COULD CHARGE A SMALL ADDITIONAL PREMIUM TO COVER 80 AND ABOVE, BUT SHOULD HAVE TO COVER ALL AARP MEMBERS. THIS LTC. INSURANCE PROGRAM SHOULD BE CORRECTED BEFORE IT GOES INTO EFFECT.

W. V. (PAT) MURPHY

AARP
HEALTH INSURANCE NEWS
SUMMER 1989
THE PRUDENTIAL INSURANCE COMPANY VOLUME 6, NO. 3

INSURANCE SEMINARS AVAILABLE TO CHAPTERS

Speakers are available to talk to AARP chapters or RTA units on the AARP Group Health Insurance Program. The information seminars require an hour to an hour and a half for the presentation and questions and answers.

The expected audience for an insurance seminar should be at least 100 persons. To make up an audience of the required size, chapters/units may hold joint meetings, or several smaller meetings may be scheduled within the same general area on the same day or consecutive days. Interested outside groups or individuals may be invited.

Requests can be made by calling the toll-free telephone

continued on pg 2

SPECIAL PHONE FOR LTC INFORMATION

If you are between the ages of 50 and 79 and are interested in AARP's Long Term Care Plan, there is a special toll-free telephone number to call for information. Dial **1-800-245-1212** and ask for **Operator 5.** You will receive details on AARP's Long Term Care Plan in the mail, including the benefits, costs, limitations, exclusions, and other terms of coverage, as well as an informative AARP booklet on long-term care issues.

Your request for information must be received by October 10, 1989.

REQUESTS FOR LONG TERM CARE KIT TO BE ACCEPTED UNTIL OCTOBER 10

An expanded AARP Long Term Care Plan, with many added features, is now available in most states. The Plan is designed to help AARP members protect their savings, assets, and income from the high cost of extended nursing home stays or home health care. In most instances, these expenses are unlikely to be covered by Medicare or private health insurance, including AARP's Medicare Supplement Plans.

To obtain an information kit about the Long Term Care Plan, AARP members should call the special toll-free number — **1-800-245-1212** — and ask for **Operator 5.**

The offer is limited and is available to **AARP members only** in most states. **Requests for information must be received by October 10, 1989. The date will not be extended.**

New features of the Plan include **inflation protection**, which **increases benefits five percent each year**, and **an optional Plan that pays higher daily benefits** will also be offered.

AARP members ages 50 through 79 are eligible to apply for this coverage. To keep rates affordable for as many members as possible, there are certain eligibility requirements, including answering a brief medical questionnaire.

Medicare provides benefits for skilled care only — whether at home or in a Medicare-approved nursing facility. This type of care is usually prescribed by a doctor after a serious illness or accident.

Long-term care is usually custodial in nature. It provides personal care for basic activities, such as bathing, eating, moving about, and getting dressed. All too often, people discover their insurance does not pay for this type of care. As a result, they are forced to deplete personal savings and, may eventually, seek the financial aid of public assistance programs, such as Medicaid.

Two Long Term Care Plans are being offered. One provides a **$50-a-day** benefit while the beneficiary is confined in an eligible nursing home, with a **lifetime maximum of three years (1,095 days).**

Under the home health care/adult day care provisions, this Plan will pay:

- **$35.00 for each covered home health care visit by a nurse or therapist.**
- **$25.00 for each covered visit by a home health aide; and**
- **$30.00 for each adult day care visit.**

An alternate Plan provides a higher level of benefits.

continued on pg. 3

Item 16

Heart to Heart
Patricia Mallott-Wood
Program Director
501-735-0870
501-735-5814

August 10, 1989

Chairman Jay Rockefellar
Attention: Steve Adelstein
U.S. Bipartisan Commission
on Comprehensive Health Care
140 Cannon House Office Building
Washington, D.C. 20515

Dear Mr. Adelstein:

Per you telephone discussion on August 1 with Betty Stewart of West Memphis, we are pleased to take this opportunity to provide information to the Commission for its deliberation on long-term health planning.

The Good Neighbor Center is a private, non-profit social service agency which is chartered to serve the citizens of Crittenden County,Arkansas. We depend on public support -- both moral and financial-- for our continued existence. One of our most important functions is that of advocating for the poor, elderly, disabled, and chronically ill. We would like to inform the Commission of our actual experience in dealing with people with catastrophic illnesses, and the health care delivery system at the private, state, and federal level.

On May 7, 1989, we received a request for assistance from Barbara Duncan, Special Assistant to the Governor of Arkansas. Ms. Duncan informed us that she had received information about two West Memphians, Rodney Pennick and Dertha "Pete" Fair, from the Arkansas Kidney Disease Foundation. These two gentlemen had received kidney transplants approximately three years ago. Post-transplant expenses-i.e."aftercare" had been covered by the Arkansas Kidney Disease Fund for the 36 month period after the transplant. After that, the on-going expenses would be covered under the new Catastrophic Illness coverage of Medicare beginning January 1, 1990.

Unfortunately for Mr. Pennick and Mr. Fair, there was no program which would cover the period from July, 1989 to January, 1990. Both men require anti-rejection medications which cost over $1,300 a month. Both men receive Social Security Disability Income checks of $696 and $760 respectively. Neither men have other sources of income, nor have they the physical ability to work at gainful employment. Because of the amount of their SSDI benefits, neither man qualifies for State Medicaid or SSI assistance.

It is obvious, on the face of the facts, that their income could not cover the expense for this medication. In our research we discovered that this is a nation-wide problem for transplant patients. The success of transplant surgery depends on the availability of these very expensive anti-rejection medications. Without exception, all transplant patients must take this medication for the rest of their lives. This is a predictable outcome of this medical intervention.

Mr. Fair is currently in rejection, probably because he has not had reliable access to the anti-rejection medications (cyclosporin, mevacor, and Imuran). If his physicians cannot reverse the rejection problem, Mr. Fair will have two options. He can go back on renal dialysis until another kidney can be found. Then he will have to undergo another transplant procedure. His chances for complete recovery and transplant success will be significantly less the second time.

Mr. Fair is lucky in one respect -- there is an option, namely the kidney machine, which can sustain his life until another kidney can be found for him. Other transplant patients who have received heart, lungs, pancreas, or liver transplants do not have life-sustaining machine alternatives. They, too, must take anti-rejection medication for the rest of their lives. They, too, must somehow find the funds to "support" their transplants. But if they go into rejection because they cannot afford the medication, they may die before another transplant is available.

Our community has made the commitment to keep Mr. Pennick and Mr. Fair in medication until January. Several civic and service groups are raising money to pay for this medication. Mayor Keith Ingram of West Memphis, the Good Neighbor Center and the Marion-West Memphis Lions and Lioness, the East Arkansas Council for the Blind, the West Memphis Junior Auxiliary, and Special Friends of the Handicapped have begun a permanent aluminum can recycling project to raise money for Mr. Pennick and Mr. Fair and others like them. We know of two more transplant patients whose funds run out before the end of the year, and assume that we will have to somehow raise enough money to get them through to January, 1990. Local pharmacists are working with us to provide the medication at cost. But these medications are very expensive, even at cost.

We were further disturbed to discover that there is a question as to whether and to what extent Medicare Catastrophic Coverage will pay for these medications next year. We have seen three different government publications quoting three different formulas. Ms. Linda Douglas, local Social Security official, has been as helpful as she can. She, too, is waiting for final clarification from Washington.

These are the facts as we have discovered them. The questions and issues that these facts raise with us are:

If we, as citizens, are committed to the saving of human lives through these advanced medical procedures, do we also not have the obligation to provide the necessary resources to the patient to survive in the long term?

In situations such as these, when long-term outcomes and requirements are predictable, should not these services be provided for in advance?

It is not good medicine or good finance to do only half the job. It is irresponsible and morally indefensible to offer people life-saving solutions and then make it impossible for them to survive unless they are independently wealthy.

A quick cost analysis shows the folly of existing policy. Taking Mr Fair as an example, he had been on peritoneal dialysis for approximately 12 years before the transplant. Public funding paid an average of $25,000 a year, or $300,000 for dialysis and related medical problems. The transplant and 36 months of aftercare cost another $150,000. So, as of May 7 this year, the public had at least $450,000 invested in Mr. Fair's welfare. This is not including other social programs such as SSDI, food stamps, etc. that have gone to Mr. Fair during this period. He needs approximately $15,600 per year for medication to sustain the transplant. If he requires another transplant, that will be another $150,000 in existing program funds which will have to be expended, and he will <u>still</u> need money for anti-rejection medication after the second transplant. The dollars and cents just don't add up! And we haven't even explored the human suffering involved. Mr. Fair is fighting for his life on two fronts--the medical front and the financial front.

Transplant patients are not the only people affected by a public policy that does not make follow-up, rehabilitative, or preventative care available. We strongly urge the Commission to examine this comprehensive aspect. Holes in the "Social Safety Net" such as we have described in this testimony are causing much unnecessary death and human suffering.

Sincerely,

Patricia Mallott-Wood
Patricia Mallott-Wood, Program Director
The Good Neighbor Center

Sherry Anderson
Sherry Anderson, Executive Director
The Good Neighbor Center

Betty Stewart
Betty Stewart, First Vice President
Arkansas Council of the Blind

The Good Neighbor Center

and
Board Member
Arkansas Division of Services for the Blind

Pat Cromeans
Pat Cromeans, President
Marion-West Memphis Lioness

Roland Stewart
Roland Stewart
Marion-West Memphis Lions

Gaye Miller
Gaye Miller, Secretary
Crittenden County
Special Friends of the Handicapped

Item 17

ARKANSAS LEAGUE OF POLIO SURVIVORS
9010 West Markham Street
Little Rock, AR 72205
Phone 501-227-0758

November 29, 1989

Senator David Pryor
C/O U.S. Senate Office Building
Washington, D.C. 20510

Dear Senator Pryor:

Thanks for being concern enough that Mr. Jennings called to request further information about Post-Polio syndrome.

Most persons with disability are living to late life, but many are experiencing the onset of new medical and functional problems. Two of the largest such groups are people with post-polio and spinal cord injury (SCI).

Post-polio individuals are experiencing primarily Increasing fatigue, weakness, pain in muscles and joints, Chronic Pain Syndrome, Temperature sensitization, Breathing, Coughing, Swallowing problems and loss of strength.

Many polio survivors, experiencing the late effects of polio, are once again finding it necessary to use crutches, braces, wheelchairs, and breath ventilators. Some are experiencing swallowing problems and being fed by tubes, and some are back in the old iron lung. The problem has, in some cases, reached proportions so severe, that the polio survivor has been forced to give up working, and/or become dependent on outside help to perform routine tasks. There are an estimated 2,000 or more Post Polio survivors in Arkansas, and approximately 1.4 million in United States. Most of these are in their 30's and late 40's. Polio individuals are too young for elderly programs, and too old for children organizations, such as, Easter Seals and March of Dimes. As you can see, they keep falling through the cracks! Those that are having to give up their jobs also lose their insurance. Securing other insurance is difficult, because this is considered a pre-existing condition. The companies that are honoring the claims, utilize extreme limitations, which are not feasible. Such as provisions for a standard wheelchair, when a motorized one is necessary to preserve remaining muscle strength.

Polio hasn't been taught in medical schools since the epidemic. Physicians today, (unless he is getting ready to retire) have never seen a case of polio, much less kept abreast of the after effects of polio. This is making it almost impossible to obtain necessary medical care. and some has been physical and mental damage by medical quackery as the field is being invaded by unskilled individuals for the sake of fast money. they being told its all in their heads (and other untrue things) after they get all the money they can out of them. This is leaving the person in state of anger, self-pity, frustration and depressed. them another frustrating search for Post Polio Clinics with answers.

The National Health Department or the State Health Department neither one is doing a thing about the problem.

Arkansas State Rehabilitation last year had several thousand of dollars left over to turn back in to the Government. and during all that year these people was begging them to help. Now this makes me real anger. NO It was easier to set on their back ends and draw their pay. You know as well as I do.there enough money that being wasted every day (State and National) that could be used to take care of these needs and others. I begging you to help me with these people. We didn't do anything but our best, so we did not deserve to have our lives ripped apart, some 30 years after we had conquered Polio!

The Arkansas League Of Polio Survivors is a incorporated, non-profit Organization. With all the powers, privileges, and immunities granted in the laws of the State of Arkansas. and of the United States governing non-profit, Tax-exempt corporation.

The objects and purposes of said organization being to provide Medical care,aid and educational information to polio survivors who are experiencing the late effects of polio. And to help them endure the problems and when possible to remedy problems.And to disseminate information about the special needs of post polio survivors to the public as well as the medical community and those caring for, or the family of those afflicted with post polio syndrome and for such similar and related purposes as may be incidental to the primary purpose. To develop ways and means of improving the lives of those afflicted with Post polio syndrome, and to do any other matter or thing consistent with law to accomplish such purposes. Above all, ALPS is dedicated to help them continue to be an independent, productive individual.

To accomplish these goals we need additional legislation and governmental support to guarantee that these and other people with disabilities are accorded the same human and civil rights as other citizens.

Since this condition is unique, the best possible care and prevention measures, need to be implemented, as early as possible. Can we please rely on you to find some kind of governmental assistance to help these people until legislation has time to enact.?

We are fortunate to have Henrik Madsen 11,M.D. Physiatrist (muscle specialist,one of the very few that is in are country) as are Medical Director of ALPS, He keeps abreast with research centers on the latest information about Post Polio Syndrome.

You will find enclosed:

- a short identification of the problems,
- a short history of the post-polio organization,
- some suggestions for solution,
- assessment of economic effects.

Thank you for your assistance and hope to hear from you very soon.

Sincerely,

Margie R. Loschke
President, ALPS

ML:mr

Enclosures

Identification of the Problems

It concerns me that we are unnecessarily losing qualified manpower and skills in this State from medical reasons. Our State's economy needs good people at work, and not at home watching "soaps."

It concerns me that there are no affordable ways to help an ambitious person with medical problems to prolong the work years in life. A lot of these people would rather fend for themselves than become dependent on premature public support.

It concerns me that there is a demonstrated absence of interest amongst our policymakers and community leaders, in preserving the productive capacity and buying power of the individual with medical problems. Our State economy would only benefit from mechanisms with Help to Self-Help. Others have done it, so why can't we?

And it concerns me that there is a recurrent degradation of human values for the individual with longstanding medical conditions. We seem to require that people become economically stripped before simple arrangements can be made. The presently available arrangements are often offered on the condition that the receiver abstain from supplementary income instead of keeping the person in his or her productive place in the community.

These are problems that are bugging our entire nation, and problems that have been debated and theorized for decades without any major results except, maybe, for some scholarly and politically biased papers.

The need for special problem solutions and the chance for successful outcome will depend on the nature of the disease, although many diagnostic groups will share characteristics. Data collected in one group may be applicable in another. Practical experience in the United States is only poorly available, and is critically missed. When I was offered the directorship for the post-polio clinics in Arkansas in 1986, I saw it as a great opportunity to show that delay of retirement is possible and beneficial to all the parties involved: patient, family, business, insurance industry, health providers, taxpayer, etc. Great effort has been invested in the early phase and the project has now reached a critical state where increased resources are needed to be able to continue in a Help to Self-help program or the data will be lost. The post-polio individuals are typically independent fighters and take pride in not being a burden to the welfare system. Their cause is not served in our bureaucratic Health and Human Resource system. The rules do not even exist that allow help to self-help to a non-impoverished person. The system is created mainly for Social Welfare and is not appreciated by a person who's highest ambition is to remain financially and physically independent. The experience stemming from a post-polio program (of maintaining the individual at a self-insured level for a prolonged time) is of positive interest for the health insurance industry and the health providers. The data will probably also indicate the grounds for some of the neuro-muscular problems that will accumulate in the over-aged population of the future, and show in what direction the solution to these problems are to be found.

As stated, the problems are very well demonstrated in the relatively small group of individuals in the United States who suffered anterior poliomyelitis during the epidemics. This group holds a lot of answers to questions that the health insurance and hospital industries have not yet asked.

It is not the purpose of this appeal to suggest additional clinical research that may never benefit any of the patients living today or the provider/payor industries, but solely for the purpose of establishing new ways of offering health services to the benefit of all the involved parties, and with immediate effect.

History of the Post-Polio Organization

For many years, special medical problems have been observed among the relatively small group of individuals in the U.S. who suffered anterior poliomyelitis prior to the invention of effective vaccines.

They are victorious survivors of the often deadly viral infection, which in many cases left the survivor with severely weakened muscles. What these individuals lost in physical abilities, in most cases they compensated by obtaining other skills. And a great number of them made careers that were above the average expected. They did not all become presidents of the United States, but they frequently became the cornerstones in our society.

Now, many years after the battle with the polio is over, many polio survivors experience secondary medical problems stemming from the scarred tissues in the muscles and in the neurological stuctures, leading to, in the more troublesome cases, that the marginal but previously sufficent muscle power is slowly being lost. The new condition is often accompanied by chronic muscle pain; extreme fatigue, leaving the patient only a few hours daily where the muscle performance is sufficent; climate sensitivity to cold and clammy weather; sleep disturbance; respiratory limitation and troublesome respiratory tract infections. Gastro-intestinal and urinary tract involvement may be present. Other parts of the nervous system such as the autonomic system may show late effects of the otherwise healed polio. The individual is no longer able to perform in his or her daily setting at work or at home without certain arrangements.

As a consequence of the problems that the individual polio survivor experienced and the fact that no medical experience in the post polio syndrome was available in the State of Arkansas, many of the survivors were forced to seek out-of-state medical support.

In 1985, the polio survivors in the State of Arkansas formed an interest group for the purpose of learning from each other the art of survival, how to remain active and productive as long as possible, how to obtain necessary medical care, how to avoid medical quakery as the field was being invaded by unskilled individuals for the sake of fast money, how to communicate the situation to the insurance carriers, how to choose assistive devices, how to adjust nutrition to the new lower energy output, how to maintain optimal use of the existing muscles, and how to arrange for the future without losing independence and without becoming relegated to welfare.

The organization was named Arkansas League of Polio Survivors, or ALPS. The organization was mainly the accomplishment of Mrs. Margie Loschke, Little Rock, who herself is a wheelchair-bound polio survivor. The organization has since its inception been in contact with approximately 520 post-polio persons in the State of Arkansas, and an undefined number from outside the State. ALPS publishes an Information and Newsletter six to eight times per year and organizes monthly meeting for the exchange of useful facts concerning the post-polio person.

In 1986, I was invited to participate in the works of ALPS and was charged with the responsibility to accumulate and update the medical knowledge in this new specialty area, to assist in establishing a clinical referral service, and to mediate patient information.

The organization's resources were from the onset very limited and all participants in the organization's activities, including the medical director, were unpaid, and the membership itself functioned in the staff capacities. The organization was, in spite of this, at an early time dependent on substantial economical support for the delivery of specialized medical services amongst its members. The insurance industry's growing willingness to accept the post polio condition as a reimbursable medical entity has however gradually improved the economical conditions for the insured postpolio survivor.

It is estimated that there are approximately 1700 postpolio survivors in the State of Arkansas. Only 520 are known to ALPS. No other practical working postpolio organization is at present time available in Arkansas, and it is therefore of utmost importance that the organization continue to receive moral and material support, as long as medical knowledge and clinical care is only limitedly available in this State.

The health-insured postpolio survivor is very well able to cover the cost for the care that he or she may be needing. The main problem lies in that physical resources and experienced personnel are not generally available. Limited services are offered by other organizations but these do not satisfy reasonable quality criteria, and should not be recommended until the quality requirements are met.

ALPS has because of insufficient resources not been able to expand its activities to all regions of the State, but is limited to the metropolitan area and with only rudimentary support to the Fort Smith area.

Some Suggestions For Solution

Solution to the problem may be found in several different forms, some of which may be excluded because of the prospective participant's dismal past performance. It is unthinkable to leave it in public hands inasmuch as public health care and rehabilitation institutions have demonstrated only failures in their attempt to deliver this kind of care, and have a documented inability to solve the cost-benefit questions.

Private organizations such as ALPS will possess the necessary motivation and ability to define the type of services considered important and worthwhile for the user, but will not be able to utilize their own material and personnel resources to such a degree that the services become cost-efficient. These organizations may not possess the necessary administrative knowledge, and would benefit from purchasing the needed services on a subscription basis from established health care providers; i.e., established hospitals, multi-specialty clinics, etc.

A reputable omni-specialist hospital who is interested in establishing itself in the specialty field of postpolio/neuro-muscular problems constitutes a third solution. Under-utilization is a fact of life in many hospital operations today. The unused resources may intelligently be coordinated to form the basis for a postpolio support service. It must be kept in mind that the requirements of such service are not absolute time-related, but can utilize the resources during the periods of the year when the general utilization of the hospital traditionally is low. Of course, from the group of post-polio patients will also be generated an amount of acute medical care that may further benefit the hospital and the admitting staff.

The ideal solution is a symbiosis between the patients' interest group and a omni-specialty hospital. It would satisfy the need of ALPS for access to resources on reasonable conditions. The organization would be able to maintain input to the question of quality of care in the daily operation via its medical director. The hospital would be able to improve its cost ratios on a part of its resources and would gain access to medical specialty knowledge on post-polio services in its geographical area. Finally, and maybe most important in today's competitive climate for health care providers, the hospital would be able to render a service to the community which is otherwise not available in this State, and at the same time as it may generate profit. This service may also become an excellent vehicle in the hospital's general marketing and in the effort to establish a new image.

Useful secondary effects may be anticipated as follows. An acute need for professional as well as patient/family information exists. A hospital with a good public teaching facility will have an excellent chance of becoming a regional care and support center for patients of specific categories. Past experience shows that well-marketed seminars for post-polio patients/families may draw 200-400 participants from the Southern region of the United States depending on lay-out.

As a coordination of the medical resources for the post-polio survivor takes place under medical direction, it is reasonable to imagine the a neuro-muscular service laboratory may be developed. Many of the components for the post-polio service will naturally address the problems that occur in other patient groups. It is reasonable to believe that the staff at this laboratory in time will obtain skills that are not otherwise available. In particular, the handicap-oriented technology of biomedical engineering and equipment application is worth focusing on.

With an increasing over-age population, neuro-muscular diseases in the rehabilitative phase will take a prominent place in the near future. A hospital without such service will be forced to relinquish an essential part of its potential out-patient earnings to other providers. Consequently, it should be easy to persuade an existing, progressive hospital operator to establish a working relationship with ALPS as described above.

Assessment of Economic Effects

Simple estimates indicate a high probability for material interest in the creation of future "How-to" clinics for neuro-muscular patients and their families.

This draft makes the following presumptions.

- The individuals involved in the program are suffering from a typical post-polio syndrome, and are referred during the period immediately following the debut of defined symptoms.
- Population: AR = 1700; USA = 400,000
- Pre-retirement is delayed by 5 years on average.
- Average yearly income at time of intervention is $25k
- Direct and indirect buying power of payroll: 4.5
- Sum of annual buying power of SS/SSD recipients = est. $80meg

1	Taxable Earning	25k*5*1700	$213meg	$0
2	Tax Revenue	213meg*20%	$42.5meg	(42.5meg)
3	SS/SSD	7.2k*5*1700		(61.2meg)
4	Medical Cost	2k*5*1700		(17.0meg)
5	Care Arrangements	2.5k*5*1700		(21.25meg)
6	Public Admin.Cost	#3 * 20%		(12.24meg)
7	Total for the State of Arkansas		$42.5meg	(154.19meg)
8.	Total for the nation		$10gig	(36.28gig)
9	Contribution to "Local Economy"	4.5*170meg	767.25meg	360meg
10	Contribution to "Nat'1.Economy"	4.5*170meg	180.5gig	
		4.5*80meg		84.7gig

APPENDIX 2

WRITTEN COMMENTS FROM HEARING AUDIENCE

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Francille B Hampton, President of Arkansas Head Injury Foundation

ADDRESS:

Fort Smith, AR 72913
City State Zip Code

Please remember the many people in Arkansas who have sustained head injury. Most are between 15 and 35 years of age. The medication and health care cost are forcing insurance rates up. Because of this those who are lucy enough to have insurance, may be forced to give insurance up. Health costs must be controled.

Direct prevention programs are needed.

Arkansas has approx. 3,000 head injuries per year.

Case management for survivors of head injury is needed. Families that are already "stressed out" emotionally and financially go from agency to agency often to find no help at all. Survivors too often "fall through the cracks"!

Francille B. Hampton

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Betty Cole Drake

The cost of drugs is a disgrace! One Rx I take is $85- per month, it has doubled in price during the last 3-4 years. The drug Co. is still being protected from it being duplicated by another Company, it's been over 10 yrs. since it was developed! Why is this?

I also pay Blue Cross premium of $266. per month with $1000- deductible (the cheapest policy for an individual. I am 62½ yrs. old and have a time to go to Medicare. There is also no stop loss benefit. I am fortunate to be able to pay this but it is hard - This makes approx. $4000 - per yr. before I can receive any reimbursement! Drs. fees, Hosp. costs, Drugs are <u>again</u> a disgrace! I also have a granddaughter with Down Syndrome. Senator Pryor, more power to you!! We are behind you - Go get 'em!!

Thanks for your concern.

Betty Drake
Arkansas Disability Coalition

Institutionalization is
no better for the older
person than it is for
younger people with disabilities

We at the Coalition find all over the state that people <u>are</u> tired and worn out with fighting the "Bureaucracy"! Wherever it might be.

NAME: Roseanna Taylor RN

ADDRESS:

Pine Bluff Ar 71601
City State Zip Code

① That necessary needs such as food, clothing, shelter, avoidance of pain, safety etc all have to take a back seat to spending money for medicines for arthritis (which they need to stay active & at home) diabetes, stomach med, heart pads etc because medicaid card doesn't cover these.

② Most older Americans in the South live on their Social Security or SSI. They get approx. $10.00 in food stamps whereas people with children may get in excess of $100's of dollars. Most of elderly must be on certain diets. They unfortuantly must spend most of their money for (cheap cuts of meat, crackers, insted of balanced meals) etc. which are not on diet

③ Need to reimburse service providers for medicaid & medicare services rendered in a timely manner. Many time services done are denied. ~~for~~ These are services that are very necessary (catheters etc.)

④ Keep Area Agency on Aging & other service providers aware of new programs in easy terms so guidelines can be understood. Ask service providers the feasibility of programs before implementing them. Try pilot programs so that rules do not change every few mths. It's very hard to give services when you never know what guidelines will be next day. For example taking the present system of assessment for medicaid personal care and changing it as of Sept 15, 1989 from a system that is working to a system where LTCAA gets paid for doing a one page assessment and service provider then must go out & make another visit for other two pages which includes clients signatures and getting the Dr's signature. 3 days is amt of time allowed to get Dr to sign Care plan (What a joke!) Ask any service provide or even Long Term Care Assesment Agency & ask them how long it takes to get a Dr's signatures.

⑤ Why elderly people who have worked hard all their lives are treated as second class citizens while children are rewarded for having children. Why when elderly people get a "raise" on Soc. Sec. their am. checks are actually reduced because their Food stamps are decreased and their allowance for housing is reduced also. The younger people end up getting more money with AFDC + Food Stamp + Housing Assistance without reductions. We had an aide in a rural town who we could give 8 hrs work 5 days per week who refused over 3 hrs per day because her AFDC caseworker told her her AFDC check would be cut if she did work ⑥ We have aides who work very hard who do not qualify for health insurance. Those who do cannot afford it. Sometimes they would come out better not working!!

⑥ Our Area Agency on Aging is one of two that do their own service. We do it cheaper. More percentage of our money goes directly to services. Rumors have it this will Not always be true. We need a System such as ~~we~~ AAASEA have so that more more is spent on services + less on people thinking up new things to spend money on. I think conferences + all the other expenses are fine in small measure but I think that more + more money should be for services + less for other needs.

⑦ People who sit in offices making up new forms to send to elderly to fill out is hard for some educated people much less our clients who most never got beyond 3rd grade.

⑧ I think case managers (if that is going to be the new trend) must be people who are qualified — not someone off the street.)

⑨ I think that elderly just out of hosp or with a temporary acute crisis of health should be able to get some personal care help temp. without having to wait for ↑ in time on care plans because crisis is usually over by time care plan is back & by then the extra care may no longer be needed. ⑩ Also on medicaid P.C. care plan one of the items is if DR's have seen client in 60 days - I think Clients should see Dr when needed. There is so much to be done but Arkansas needs to stop spending so much time & money on making up new forms, programs etc & take that ~~to~~ money to the people who need it.

I realize there are unscrupalous people out here so there has to be guidelines but I think we get so caught up in guidelines & tons of paperwork that the time + money available to help people slowly diminishes.

Thanks for your time

Roseanna Taylor RN
Area Agency on Aging South East Ark.
Pine Bluff Ark

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Mrs. John B. Crockett Jr. (Member of Ark. Head Injury Foundation)

ADDRESS:

Knoxville, Ar. 72845

City State Zip Code

Deeply appreciated is your interest in this field that most persons will one day face to some degree in life - thru age, disease or accident.

However, I and others came to this meeting only to find that once again the group with Traumatic Brain Injury that totals more than most other diseases put together were not represented. Our people stood up to share their stories. They should have had a representative. This problem is national. It effects children to adulthood. It, like with the elderly & other diseases, is devastating to the survivor and total family for a lifetime. There is little help in information, trauma care, rehabilitation (who can afford over $500 per day.) re-training for jobs, job support help, in-home help ~~in home~~, help in counseling, an ear that (has been there) who understands these unique problems. With head-injury, you do not hurry up and wait - Delaying treatment and supported rehabilitation destroys a chance to have a victim back into-the-mainstream — Removes, regressing to a rest or nursing home where personnel is not trained for this type care. ______ or death. This is so personal! So important! - Yet, until it comes 'home' to your family its easier to consider services already in place. The Long Term Care should include as one of its top priority one of the largest groups caught in the disaster of catastrophic illness expense. These only ask for help to help themselves. They deserve your attention, your concern, your fight for them! Please help us!

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Kaye Curtis, Director of Aging Services
ADDRESS: Northwest Ark. Economic Development District, Inc.
P.O. Box 190, Harrison, Ark, 72601
City State Zip Code

One critical need for our elderly with Altzheimers,
Dimensia, etc is more secure funding for Adult Day
Care Centers. My agency operates nine senior centers in
five counties in the Northwest part of the state. We have also
opened two adult day care centers during the past
four years. Although limited funding was given to start
each of these "pilot" projects, we must struggle to keep
these programs going - which means we are unable to
expand the programs to serve the ever increasing numbers
of elderly and their caregivers who need respite
and day care services. Budgets for the two day care centers
for 1990: Baxter County Adult Day Care, opened in 1985, has "
budget including $30,000 of state funding; Boone County
Adult Day Care, now being established with clients being
served for first time during the first week of September,
"annual" funding of federal funds in amount of $6,000.00.

Although I agree that the communities & sponsors should "Take
Care of their own elderly", I also recognize the growing

numbers of elderly with special needs who do not want to be institutionalized should have the choice of staying in their homes. Due to our present limited funding and certain regulations we must meet, we cannot expand services. I agree with the regulations but feel more funding should be available to obtain the facilities and staffing necessary to serve more elderly. Due to present facility and staffing limitations, we are licensed to serve 15 clients per day. Our area of the state is the choice retirement location - which means the numbers of elderly needing care is growing annually.

My suggestion is to place adult day care on the priority list to receive secure funding each year.

Another problem I feel should be addressed is the one of the ever increasing need and demand for Home Delivered Meals. In the past seven years, our senior centers have experienced demands for meals for the homebound that is becoming more and more difficult to afford. Seven years ago, the senior centers prepared and served 85% of their meals to people coming to the centers and 15% were delivered to the homes. Today, we are serving an average of 51% of meals at the centers and 49% are delivered to the homes. Yet, our federal funds are being cut while our demands for services are increasing. Demands for transportation services are also increasing. Our levels of donations from clients at the nine centers are now in excess of $60,000 per year - which shows the clients are willing to help pay for services. Please do not cut our funds further!

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Maybelle Bledsoe R.N. RSVP AARP & GSOP

ADDRESS:

Texarkana AR 75502
City State Zip Code

Thanks, David, You are doing a good job!

One thing that I would like to be cleared up in N.H... I believe it should NOT be mandatory to pull the very old, very debilitated residents out of bed 5:30 AM to go to the dining room for breakfast. This is fine for menumum care, or in some cases intermediate but for the very old, ill, nearly blind that cannot speak for themselves this is BAD. Oftentimes they fall asleep in their oatmeal. I feel exceptions should be made. most are not mentally able to make the decisions. I feel the Nurses would better be the judge of their condition: Those mentally able flatly refuse. I would hope we could put ourselves, our loved ones, in this situation in our minds. To keep these dear, old people up so long is WRONG. By the time breakfast is over it is Bath time, then soon thereafter lunch time, after 5:30 to 1:00-2:00PM before rest time. One aide to 10 or more cannot do one to one care,

Thank you. (I am writing on my knees).

God Bless.

P.S. These people should be allowed to have breakfast in bed... rest until bath time... they do need this.., esp. those who cannot feed themselves (Spoon feeders). To sit so long would be hard on a young, healthy Person. Please allow the Nurses to make this decision.

NAME: VIRGINIA SHIRAS (Mrs. Pete Shiras) formerly of Mountain Home (Baxter Bulletin)

ADDRESS: Arkansas Department of Health

Little Rock AR 72201

City State Zip Code

It was a good hearing!

In considering the services available to rural Arkansans, please don't forget that the County Health Units of the Arkansas Department of Health (Public Health) provide Home Health and other In-Home Services in most counties in the state – as we have done since 1918. There are other home health agencies in the 6 counties that we do not do home health in (Pulaski & a few in W. Ark. – Ft. Smith/Fayetteville area).

I am now working in the state health department's Home Health/In-Home Services program.

Thanks for what you are doing!

Virginia Shiras

NAME: Mrs Mary B. Parker

I agree with the Witnesses. We Need "Home Care" Expenses for the aged so They may stay on in Their Homes & Not have to go to the Nursing home to get Care.

We also need nurses, & Aids who may go to people homes in Arkansas As in Wisconsin state. Even when people over 60 years of age leave The Hospital after operation or Illness. Nurse take care of Their Health & The aid Comes & clean Their House & Wash clothes. etc.

NAME: Robertha Rasdon

ADDRESS:

Springdale, Ar. 72764
City State Zip Code

Help needed if the elderly and disabled are to remain in their homes, and this is Cheaper on the tax payers. ~~and~~ The People are more Content. In-Home services, low rent housing, transportation, (Transpotation on a one to one basic). Help with the forms needed to obtain these services. Fringe benefits for the Home-makers or Nurses aides needed to help the people in their homes. Home delivered meals in the more remote rural Areas. Change the guide-lines on financially on who are ~~[illegible]~~ elegible for Care in their home. Make the financial guide lines the Same as for Nursing Home Care. The discredency is apalling.

Robertha Rosdon
Case Manager with
Area Agency on Aging of N.W.A.

NAME: Curtis L. Mason **DATE:** Aug. 23 1989

ADDRESS:

North Little Rock, ark. 72116

PHONE:

****

COMMENTS: Early last year at the town meeting held at Indian Hills Bapt. Church, you said Senator, that you expected some action on the "Notch years" ~~recep~~ recipients of Social Security in 1988. Has or will there be anything done on this. It seems Grossly unfair that some of us should be discriminated against because of this.

Thank you.

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Edith L. Altheimer, LCSW *

ADDRESS:

Little Rock Ar 72212
City State Zip Code

Service delivery to the elderly @ best is fragmented. It is important that an appropriate forum be available to bring all segments together to address the needs & concerns of elderly. Frequently local, state and federal agencies have conflicting regulations which places the elderly person in growing conflict. It is likewise important to include persons with knowledge of the issues & less appointment of political "favors."

* Licensed Clinical Social Worker
VA Medical Center
Acting Associate Chief, Social Work Service

NAME: Patty Hulse

ADDRESS

Pine Bluff AR 71601
City State Zip Code

As the In Home Service Supervisor for Area Agency on Aging of Southeast AR I would like to voice my flustration with the System. At the Agency we struggle daily trying to find services for everyone who calls needing help, but due to a lack of funds from the state + federal sorces there are MANY Non-Medicaid people who fall through the cracks. The guide lines for Non-Medicaid client are to strict. And guide lines for Title V Aides are to strict. With a little more money + less strick guide lines we could serve many more of those who fall through the cracks.

It seems every year there is less money + we are able to help fewer people.

I feel that when you work your whole adult live + retire there should be help for our Seniors without their spending their life savings. I would gladly pay more taxes to see these people cared for.

I would suggest the Pepper Commisson speak to the Provides of Personal Care to find out how they feel + get their suggests as to how more people can be helped.

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Rita Munn Jones, LCSW

ADDRESS: th

North Little Rock, Ark 72209
City State Zip Code

As a VA Clinical Social Worker, I'm finding that many veterans + families are falling between the cracks, due to the implementation of the Means Test. Many feel that when they served their country, they were promised medical care, not Means Test Eligibility. One such case: Annual Income of $13,000; monthly Bills of $1,600; + stocks + bonds of $15,000 from which $360 a year interest is earned. This family cannot afford Dom care or Inpatient Services (over) for an Alzheimer's patient. Please address this as too many veterans are <u>hurting</u>. I hurt too, when they are denied service due to inability to pay.

NAME: Celeste Swift, RN, PHN, MSN, MSW

ADDRESS:

Orange Texas 77630
City State Zip Code

Re: Mr. & Mrs. Ralph R. Swift of Booneville, Ark, my parents. My father is 78 years old and receives $\$209^{00}$ Social Security each month. He received a 2^{00} cost of living increase and an extra charge of 4^{00} for catastrophic illness insurance. My mother is 73 years old and receives $\$96^{00}$ a month social security. She has Never received a cost of living increase. My father wants to know why a person receiving a small Social Security check in never given a cost of living increase.

I personally left Arkansas to be educated & worked in California & Texas assisting and teaching health care. At this time I would love to come home to Ark. or go to Washington to better serve rural America.

Thank you,
Celeste

NAME: Helen B Boykin Pe

ADDRESS:

Little Rock Ark. 72209
City State Zip Code

i live in a low incom Husin Complex
i have live there Since 79,
i live on a Small incom of $354. a month
Since (Sec 8) toover my Rent go up Every. year.
Every time my S.o.C. check ~~go~~ up so does my Rent.
But i have no orther Place to live. i am very
glad to have a nice Place live

NAME: Elnora M. Sherman

ADDRESS:

No Little Rock AR 72116
City State Zip Code

Teach the youngest child to be helpful!! Use everyone as part of solution. As example:

1. small child can visit + do art work.
2. Kids can run errands + do yard work.
3. Teenagers can read for and answer letters. Keep in touch with friends and relatives.
4. Adults can listen and do many things to help with exercise, sewing, telling current events. The local extension meetings could be ~~tele~~ video taped + shown to the people unable to attend.
5. The prisoners can grow enough food (the good kind like is served in Cummins Prision) to make meals for the elderly. These can be frozen and used by the individual, care giver etc. One of the most difficult thing is take care of someone and cook too.

NAME: Joyce Harms

ADDRESS:

Little Rock, AR 72205
City State Zip Code

Basically, health care of a family member is the family's responsibility — Not governments!

Permit people to earn and provide for themselves.

Do not make people who have provided for 'health care' and 'Old Age' pay for those who have not — Repeal your Catastrophic Illness Program!

NAME: Elizabeth F. Davis

ADDRESS:

Texarkana Arkansas 75502
City State Zip Code

As one of your elderly constituents, I am asking you to please address the problem of physicians charges. Thank you for considering the issues affecting older Americans as a high priority — long term health care.!

NAME: Stella Payton

ADDRESS: No.

City LR State AR Zip Code 72204

I believe dental care is a Very important thing for Older people ~~that~~ has been Overlooked. #1- The Costs are Astronomical. #2. I Know Older people who Cannot afford 1 or more teeth that are Missing. #3. I heard an Older lady say She had to somehow get a blender if She Continued to eat right - and on + on + on Please do Something about it!! Thanks

NAME: Juanita Walker

ADDRESS:

Little Rock Ark 72206

City **State** **Zip Code**

Dear Senator why do we have to have a
Doctors statement to get a Loan?
I thank god for some one have been praying
for the Elderly people. I am in that
situation. I am certainly praying for
this Program. may god bless you in
your Endeavors.

NAME: BILLY C HARRIS

ADDRESS:

Searcy AR. 72143

City **State** **Zip Code**

I would like To See more efforts made To cut back on The U.S. military presence in S. Korea, W. Germany and other countries our presence is Neither Needed Nor Wanted There and The monetary Savings would be Tremendous.

More funds could be available To help with domestic problems: homelessness, drugs, health care.

I Appreciate your efforts on this issue.

Sincerely,
Billy C. Harris

NAME: TILLMAN WALKER

ADDRESS:

N. LITTLE ROCK | ARK | 72116
City | State | Zip Code

I DON'T MIND PAYING MY PART BUT BECAUSE I SAVED
FOR YEARS FOR MY OLD AGE ENJOYMENT. NOW I HAVE TO PAY
OTHER MEN I WORKED WITH INSURANCE. BECAUSE THEY DID
NOT SAVE AND DON'T HAVE TO PAY FOR CATASTROPHIC.
INSURANCE. NOW THEY TELL ME ABOUT IT.
I PAY FOR MY WIFE + I $\$31^{90}$ EACH A MONTH MEDICARE, +
TRAVELERS INSURANCE FOR SUP. INS. $\$154^{00}$ A MONTH FOR US
AND I AM BEING TAKEN ABOUT $\$800^{00}$ FOR CATASTROPHIC INC.
A YEAR. I KNOW YOU CAN SEE MY POINT.
JUST REMEMBER I VOTED FOR YOU EVERY TIME YOU RUN.
AND PLAN ON DOING SO UNTIL YOU RUN FOR RELECTION.
I HOPE YOU WILL BE ANOTHER CLAUD PEPPER.
ALSO INSTEAD OF SENDING OUR TAX MONEY ALL OVER THE
WORLD, INSTEAD LETS SPEND IT AT HOME.
I HAD HEART ATTACH 30th DEC. 1981. I WAS GIVE MEDICINE
INSTEAD OF BY PAST. THIS MEDICINE COST PER HONDRED $\$20^{50}$. NOW
THEY COAST $\$39^{95}$. I TAKE TWO A DAY MY DROGEST SAID IT IS
WAY TO EXPENCE. THEY ARE RIPPING US OFF.
ALL THOSE PEOPLE IN OUR U.S. GOVERMENT STEALING FROM
OUR PEOPLE TAX. YOU + OUR CONGRESS SEND THEM UP FOR
LIFE WORKIN ON A ROCK PILE. INSTEAD OF A HOLIDAY INN TO LIVE
IN. LIKE THEY DO NOW.

Tillman Walker

NAME: Norma J. Stuart

ADDRESS:

Sherwood, | Ar. | 72116
City | State | Zip Code

Question:

Why does Medicare pay Drs. so little??
The Drs. don't want Medicare patients +
Charge others higher price because of this.
We need to spend this country's money
on our people.!! First!!

NAME: Ruth Varner LSW

ADDRESS:

Springdale, Ar. 72764

City State Zip Code

Senator Pryor,

May we have your help to get more inhome care or residential care for the elderly. and World War II Veterans Medical care.

I am a hospital Social Worker, retired, and see so many people go/sent to a nursing Home when they could remain in their own home with help or financial help to live in a residential care facility with a great savings to the State of Arkansas.

I appreciate your much help in the past and glad you represent Arkansas.

I serve on the Gov. Adv. Council on Aging so respect your efforts.

Thank you,

Ruth Varner.

NAME: JACK HARRIS

ADDRESS:

SEARCY AR 72143

City State Zip Code

LET JAPAN AND THE EUROPEAN NATIONS ASSUME RESPONSIBILITY FOR THEIR OWN COLLECTIVE DEFENSE. KEEP A MINIMUM NUMBER OF TROOPS IN KOREA AND OTHER POTENTIAL "HOT SPOTS."

KEEP THE PRESSURE ON THE PHARMACEUTICAL COMPANIES TO KEEP THEIR DRUG PRICES IN LINE WITH THE COST-OF-LIVING...

NAME: Gail Grice

ADDRESS:

Little Rock AR 72207
City State Zip Code

Dear Senator Pryor,

As an employee of the Arkansas State Unit on Aging, I see many cases such as those presented in this hearing. We at the State Unit want to give those services to older persons; however, we are also bound by budget constraints. We need your help to keep older persons in their homes. We need a more comprehensive effort to take place to benefit all of us.

NAME: Jack L. Hubbard

ADDRESS

Benton AR 72015
City State Zip Code

I do hope that before I pass from the scene, the United States will establish a national health care system, similar in quality and equity to that of our neighbor to the North, I understand the Canadian health care system is a fair and equitable system and that Canadians would not exchange it for any other plan public or private, that might exist South of their border.

Jack L. Hubbard

NAME: Freda D. Heard

ADDRESS:

Jacksonville, Ar 72076

City State Zip Code

Pursue Senator Kinard's
"911" one Stop Info and Help
I Recently completed 4 yrs As
my husband's CareKeeper —
and it has been most frustrating
We have too many Trying
To do Too much and not
Too many that have any Knowledge of
what and how To do anything
that would help a stressful
Situation

Thank you Senator
Pryor For your Time

NAME: G. L. Purtle

ADDRESS:

Conway, Ar 72032

City State Zip Code

Financing of the catastrophic benefits by a surtax on senior citizens is very unfair and should be re-financed.

Prescription drug costs are out of control and should curbed.

NAME: Mrs Inez Godwin

ADDRESS:

Little Rock | Ark | 72207

City | State | Zip Code

Senator David Pryor,

Thank you for holding the Long Term Care in Rural America in Little Rock.

I was impressed especially with Dr Rosalie Kane - She knew her subject and chose to use terms that older people understand.

I have to share a concern of all Arkansans - please keep your involvement with the Pepper Commission - you know the needs of older people and you have the patience to uncover the inadequate laws that govern this agency.

Inez Godwin

NAME: Tommie Lee Lloyd SR

ADDRESS:

Little Rock | AR. | 72204-1914

City | State | Zip Code

I need money to pay MY bills?

I need money to buy A Homes

I need money to pay MY DR. bills

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Zula Mae Porter

ADDRESS

Morrilton, ark 72110

City State Zip Code

Meals on wheels -
Cut off those who
are able to feed themselves
They own good homes good cars
have bank accts. they can buy
Their own meals. little over
Am 74 yrs old have income of
$400 S.S. & Rent. & all my utilities
pay $200.00 Rent. a live in Smith-
I give [illegible] since we retired.
elderly people since this.
I paid in S.S. so I go to these centers
I feel guilty if
eat free meals.

Too many food ~~stamp~~ stamp young people
they can buy better food
than I can buy.

Employ honest people at head
of all ~~[illegible]~~ programs. They
[illegible] friends & senior people.
Your programs are as good
as help you employ. this
was my motto in my business.

Rest Homes are poor
[illegible] [illegible] paid not
I worked one yr. as I want
to see all the conditions in my area.
to live in peace in these fields
I'd love to work in these fields.
my daughter is interested too.
She un-employed now -

NAME: LYNN DONALD **DATE:** 8/22/89

ADDRESS:
SPRINGDALE, AR 72764

PHONE:

****

COMMENTS:

Senator Pryor, I am the mother of an eight year old little boy who was injured at birth & has severe physical & mental disabilities. I am somewhat disappointed not to have some testimony from someone representing the developmentally disabled. However, I believe those who spoke represented many of the same problems that those of us with sons & daughters with disabilities living at home with us face. We are in desperate need of both state & federal help & support in providing care at home! We need passage of the Chafee Bill - the Medicaid Home & Community Quality Services Act. We need a re-evaluation of the government's willingness to spend so much on institutional care for the disabled, yet almost nothing to support families for whom institutional placement is an option they do not seek. People need choices that make sense - Each of those people who make too much to qualify for services - bankrupting in the care of a loved one is no choice. I also want to mention the extreme need for some form of independent case management to help those with special needs negotiate a hostile (I believe this) and unresponsive - an intimidating & disrespectful system of services.

Sincerely,
Lynn Donald

NAME: Wanda R Hogue

ADDRES

Pocahontas, Ark. 72455
City State Zip Code

Senator:

Both my parents are over 73 years old. My mother uses Nitro Dur II Nitro patches as a result of a heart attack in 1983. The cost of these have increased from $26.50 in 1985 to 36.00 in 1989. This is a months supply.

Together they take over $150.00 a month in drugs. Fortunately they have a supplemental insurance that pays for prescription drugs.

My Complaint is physicians who won't accept Medicaid & Medicare. Elderly people have a hard time understanding how to submit their bills to get their money back.

I believe doctors should be paid enough under Medicare & Medicaid so they could be required to accept these & bill for the service.

My mother often say that if not for me to get their forms filled out and to interpret their responses that they would be bankrupt. Unfortunately many elderly do not have someone to help file & interpret Medicare forms. The process should be simplified. If we can use a plastic credit card to charge why can't a system like that be set up for Medicare & Medicaid to eliminate paper work for both client & physician

Thank you

NAME: Karen H. LAWMAN, LCSW

ADDRESS:

No. Little Rock, Ar. 72116

City State Zip Code

In Ark. the VA has always provided a wide array of services to the elderly veteran. Recently, due to budget constraints many veterans are unable to receive benefits due to having income above the Means test standard.

The Medical Center has qualified professional staff who feel frustrated by this. We have wards closed due to the lack of patients to fill them. The old Roosevelt Rd. Hospital stands empty & could certainly become a residence for the homeless.

As a Federal employee for 25 yrs. I feel very frustated by the lack of concern for the veteran.

I'm sure Abraham Lincoln has turned over in his grave many times c̄ the lack of care or caring for the veteran, his widow & his children.

The long term chronically mentally ill now have no place to go c̄ the Long Term Care Assessment & standards.

When I started my career with the VA, we were a "service" organization providing care to those who gave us our freedom. Now all we hear is how this service or that is not making us (VA) any money. We have certainly lost track of the Argonne Forest, Iwo Jima & Vietnam.

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Dorothy Becton

ADDRESS:

Little Rock AR - 72217
City **State** **Zip Code**

Senator Pryor:

We __do__ have a critical problem in this country with health care costs.

The individual can't afford to be ill.

The solution is not another tax-funded program.

We need legislation that will prohibit excessive profits by health care purveyors Insurance companies, Doctors, Pharmaceutical Cos Hospitals, Nursing Homes, etc. We do not need new programs, but additions to existing programs and even Federal assistance for poor states - such as ours.

Providing for our families must continue to be individual responsibility, and those of us who have sacrificed to prepare for the future should not be penalized. Our children, entering the work force today already inherit a tremendous debt

Let's solve this problem in another way. We must focus on community involvement. Chronically ill persons will include drug affected persons, which will become the number one health cost problem in this country.

David, you invited me to participate in this hearing, but I do not feel that my opinion was expressed here today. Only one side of the story was told. I feel you should give equal time to those of us who will be paying the bill.

You may not recall the Social Security Regional Meeting in Dallas that I chaired a few years ago - you were the Keynote speaker from Arkansas.

Again - We Do have a critical health care costs problem, but a Tax-funded program is not the answer.

NAME: Linda Orr **DATE:** 8/23/79

ADDRESS:

Searcy Ar 72143

PHONE:

****

COMMENTS: For the last four years I have listened to story after story about the long process of getting Medicaid. I have been involved in the health care business or some part of it for almost nine years. I have filed all types of Insurance, Medicare and Medicaid and I came today to tell you that your Medicaid system does not work! I have filed claims up to 32 times only to see it be denied time and time again due to filing. I have also sent claims to the Medicaid office registered mail where they were signed for only to disappear in the ~~[illegible]~~ office. I have been told "off the record" by girls in the Medicaid office that they get back logged on a supervisor's desk only to be thrown away or denied due to timely filing when in actuality the claim was in the Medicaid office on time. Hospitals are eating millions of dollars each year in bad debt accounts. The public is being misinformed also. Social Services informs people every day that if Medicaid doesnt pay they are not responsible that is not so. If the individual has been to a privately owned hospital, he or she is still by law responsible for that balance of for any reason their Ins. or Medicare or Caid doesnt pay. I feel for you, talk about being caught in the middle.

Unless Medicaid simplifies their forms so even their "TRAINED" personell can file correctly it will not do the public any good to go through the long process of getting Medicaid.

During the last presidential election debate it was very hard to sit in front of a T.V. and listen to two possible leaders of our country argue about Medi Especially when neither of the two seemed to know one thing about it.

I do not claim to be an expert on Medicaid, however I do know if it takes 32 times of filing a cla only to end up in a trash can, only to turn aro and have to bill the patient then we have a problem within the system already there.

Fonda Orr

NAME: Lola West LCSW

ADDR:

No. Little Rock Ark. 72116

City **State** **Zip Code**

Care for the elderly in Arkansas is fragmented & ambiguous at its best. To begin to correct this situation the attitude of our leaders must be changed (by education). First of all care of the elderly, chronically mentally ill, & handicapped children is not cost effective & should not be judged in such a manner - Ask anyone from Uncle Ben who is an SSI recipient to someone in the private sector - What is your elderly, chronically mentally ill or handicapped person worth and they would reply priceless. They are! Let us organize & centralize care for these individuals - stop the territoriality - we have enough of these folk to go around.

For elderly veterans in Ark - my particular interest - services are being seriously affected due to budget constraint, and arbitrary eligibility requirements. An elderly veteran is an elderly vet & in need of services even if he had the good fortune not to be service connected due to mental or physical wound. For Adult Day Health Care, medical services, Home Based Hospital Care, etc. the provision of services & the length of service provision should be based on NEED not Service Connection or Category eligibility. Health care for all veterans has become difficult & frustrating to access. We need to go back to the basics of caring for our veterans. Vietnam veterans are facing extreme difficulty in ~~acc~~ accessing long-~~ter~~ Term care as are our elderly veterans.

Those of ~~we~~ us who are health care professionals as well as individuals who will be or are careproviders are dedicated to improving health care services and look to you to carry our problems & suggested solutions to our ~~laws~~ policy makers.

(I would suggest you speak with some Ark. vets. concerning the quality (lack of) care through the VA emergency room & evaluation clinic at LR VAMC)

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: GWENDOLYN W. STARLARD

A very timely hearing. Much needs to be done in the area of Long Term Care. Your efforts are commendable. The elderly need all the assistance they can receive in order to live their latter years with dignity. Services must be made available and at the least possible cost.

NAME: Lottie Smith

I am the widow of world war To Veteran [illegible]
he husband died will Be 20 years Sept 1st
Labor day 1969 I may get $30 monthly 323 Social
Security I need Dental work I can't afford Get
it Done why Can't the Government allow the Widow
More Why this when we have Bee cut
to Esy 3 month

NAME: Charles F. MARCROM

People who Draw less than $700.00 or $800.00 Dollars A Mo. Retirement or Disability Can not Afford to pay For Medicare or Co insurance?

Also I would not Care to pay $800.00 A year if I had A Income of $35,000 A year to Live on

Charles F. Marcr

NAME: Raymond Elandt **DATE:** 8-22-1989

COMMENTS: Stop the abusing + the privileges
of the Med. Care + Medicaids, by the
doctors + drug companies
We must controle the prices
of druges there should be a fair
price

NAME: [illegible] Wardl

CONGRESS SHOULD MAKE A STUDY,
INVESTIGATE THOROUGHLY, ADOPT THE
HEALTH PLAN IN USE IN CANADA

NAME: Jane Browning **DATE:** 8/22/89

COMMENTS: The issues addressed in the
hearing — the need for at-home care
services, personal attendants, independent
case management, universal health
insurance — apply equally to
younger persons who have chronic
disabilities. My ~~sone~~ son is only
6½ but has Down's Syndrome;
his needs will be lifelong. I
seek a national health system that
moves AWAY from its institutional
bias and towards supporting
individuals (+ their families) at home.
I thank Senator Riegle for his
co-sponsorship of Senator Chafee's
Medicaid Reform bill and
his interest in my son's future.

NAME: [illegible] Geraldine Lyons **DATE:** [illegible]

COMMENTS: Medical coverage [illegible]
As far as paying medical bills [illegible]
for prescription [illegible]. Thank you for
all you're doing. Medical insurance
is too high cost to average [illegible]

NAME: CODY E. STUART

ADDRESS:

SHERWOOD AR 72116

City State Zip Code

Dear Senator Pryor:

I wish you would explain to me how you ~~how you~~ can justify in your soul to vote for a bill that increases my income tax by 26 percent in 1991. I believe you are an honest and sincere person but you sold out a few elderly for political expediency.

How can you justify continuing to give money to Israel to start World War III and raise the taxes on some elderly by 26 percent.

Recommendations for financing elderly care.

1. Stop the wasteful spending by the military industrial complex.
2. Stop giving money to every nation that asks for money.
3. Stop trying to police the world and stop trying to force our form of government upon other nations.
4. Reduce government programs that we do not need.

NAME: SIGNED

ADDRESS:

City State Zip Code

Please do more than check into Canada's health plan insurance - Adopt it! Out (to) AMA

Work Toward Home Living Care - help!

Cost of drugs - Doctor's order too many drugs - also change medications Too often?

NAME: Louise Alexander

ADDRESS:

Texarkana Ar 75502

City State Zip Code

I'm writing you a letter about the catastropic? ~~catastropic~~ Heath Ins. Legislation— the spousal part is good & so is extended Hosp care, but the taxation part is all wrong— Even the young be effected by this. This should be stretched out generally instead of 40% bens, paying for the other 60%—

What can we do about high cost of Hosp, Dr's bills & Medicine?

NAME: HAROLD E LIPSMEYER

ADDRESS:

MORRILTON ARK 72110

City State Zip Code

AS A 27 YR VET, why is it that we are being DENIED, ALL MOST ALL of OUR DENTAL CARE?
TRYING To Get AN Appointment for medical At L.R.A.F.B. IS Next To impossible.

AS LONG AS time EXIST, Ret military were ASSURED of those Two benifits

Last year I spent from my own pocket over $2000.00 for dental care, the AFB NOR VA would PROVIDE The SVC

AS of this time lots of us are starting to Reach that magic AGE. I'm 60.

NAME: Luther L. Grimes

Dear Senator Pryor

After hearing the testimony of the four ladies I have decided my problems are very minor. The only thing I have to gripe about is the way our workmens comp laws interfere with our Social Security. workmans comp is a form of liability just like auto Ins. The difference is if I get run over by a semi truck & collect a million dollars, not one cent is offset by Social Security. But in my case, I settled a workmens comp case & they are offsetting 900.00 per month of my S.S. benefits untill I'm 65 years old. I'm 60 now. This is absolutley unfair. If a person collects $100,000.00 in workmans comp. It should not be offset, anything above that amount should be offset, regardless of the who's liability. Now, Let me thank you for the interest you & your staff showed in my disability case, especially Kelly. We love all of you & support your efforts to change things for our good & welfare.

Sincerely
Luther Grimes

NAME: KENNETH A. HARRIS

ADDRESS:

JACKSONVILLE AR. 72076
City State Zip Code

I WOULD LIKE TO KNOW THE STATUS OF THE BILLS IN BOTH THE SENATE AND HOUSE OF REPRESENTATIVES THAT WOULD ALLOW UNIFORMED SERVICE DISABLED RETIREES TO RECEIVE BOTH RETIRED PAY AND V.A. BENEFITS. WE ARE THE ONLY FEDERAL EMPLOYEES WHO ARE FORCED TO PAY FOR OUR OWN V.A. BENEFITS.

Kenneth A. Harris

NAME: Buford Stinnett

It Seems to Me that if We are able to Put a Man on the Moon, we Could Create a desent health bill. I also feal that must not only be a health bill, but a bill of afford ability. for Private, Federal, State, local, and individually. I also feal that this must include what is best for the spicfic Person.

NAME: [illegible]

ADDRESS:

[illegible] City [illegible] State [illegible] Zip Code

Interested in what you are doing about the people who are born in the "Notch years". I [illegible] and am very distressed over this not being corrected. I am diabetic, recently tested positive for Lupus and my medical bills are outrageous. One prescription [illegible] a mo. Not to mention all the medical for the diabetes. My test strips are $55 for 100 & I use 3 a day. Please let me know what is being done on this "Notch year" problem.

Thank you

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Robert D. GARRETT

ADDRESS:

Benton — Ark. — 72015
City — State — Zip Code

Everyone favors long Term care - Do not overlook the "notch" year citizens.

1. They paid social Security from its inception until retirement.

2. One-half of the social Security benefit is often deducted from Their employment retirement benefit.

3. Most of Them were subjected To service in The armed forces during W W II.

4. One-half of our social Security is already Taxed.

5. The catastrophic care calls for a sur Tax on our income - A small % of Those over 65 pay The majority of The cost.

If The elderly pay The entire cost possibly farmers should pay all The farm cost, etc.

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Shirley Norman

ADDRESS:

Little Rock, AR 72205
City **State** **Zip Code**

Senator Pryor,

Thank you for your time and effort in solving the tremendous problem we have with aging America and all the problems that comes with it.

I too have parents who are aging and are beginning to have health problems that are exhausting their incomes. They as many older Americans lived for a long time believing that as we grew older, life would get better. Unfortunately, this has not been the case. Medical bills and the cost of drugs exceed their incomes.

Like most children of ill parents, I do what I can. But taking care of my own living expenses is about all I can do. Guilt will not pay bills. Therefore, it would be a tremendous help if a Federal or State program would be establish to aid those who are just above the poverty level in income. Shirley Norman

If you have any additional comments that you would like to express to Senator Pryor, please use the space below to make your opinions known.

NAME: Ann Gaston PhD

ADDRESS:

Little Rock AR 72211
City State Zip Code

The stunning testimony of the caregivers and recipients of long term care, as well as the data my staff & I are collecting in a VA funded research project on coping abilities of caregivers of older veterans vividly portrays the need for legislation which will ease access to long term care. Much is needed in the way of financial support for home care services & support for caregivers. Your investigation of pharmaceutical companies & escalating drug prices is much needed. Even with increasing alternatives for caring for the chronically ill in the community, there will always be need for quality care nursing homes, ~~placements~~. I would hope that with the grand swell for community services, we do not forget the need for increasing quality of care in long term institutional settings. The regulatory system needs to continue & to be strengthened & staff properly trained & reimbursed

Another concern is the lack of community mental health services for those who will be expelled from nursing homes per recent legislation. There may be difficulty in complying with law if alternative sources for financing community mental health services are not found.

I appreciate the job you are doing & am particularly pleased that I was able to attend the hearing in Little Rock.

NAME: Chris Alexander R.N.

ADDRESS:

Clinton | Arkansas | 72031
City | State | Zip Code

The Meeting of Long Term Care in Rural America was most interesting, well planned. Very informative with the 4 women on the Panel. I have been an RN since 1935 - Served in the Army Nurse Corps for 23 years and Retired worked in the local hospital until 75 years of age. Now Volunteer in the Van Buren County Nursing Home - I know the families do not desire to place their loved ones in the Nursing Home but they are so capable, giving excellent care and a real necessity for the Community. These employees in these Nursing Homes are dedicated loving individuals giving excellent care - Senator Pryor the hospitals in the cities received 100% for care of a patient with Pneumonia for instance, while the Rural Hospital only receive 60% Why is this? It was a real pleasure attending this meeting - Thank You —

Chris A

NAME: TOM FULMER.

Senator Pryor

It seems that every time Budget time comes up the first ones they want to penalize are people on fixed income and our Social Security benefits

As for myself I have worked from the age of Eight in 1937+38 and Contributing to Social Security since it began but because of trying to better my position in life I took a job with a government agency (the Postal Serv.) and now that I am at retirement age after working under Social Security for some 30 to 35 years the government wants to reduce my Social Security amount 40 to 60% because I am retiring from a government agency. Voting against any of these bills would be appreciated

Respectfully
Tom Fulmer

NAME: Ellene Davis

ADDRESS

Hays Kansas 67601
City State Zip Code

Mental health centers do not serve the needs of the elderly. I do not believe that the majority of them will ever do so voluntarily. Therefore I recommend that a requirement be written into a federal regulation that would require all Mental Health centers to have an elderly specialist on staff and budget to support elderly programs. Preventive programs are needed as well as treatment services.

I am an Area Agency on Aging director in a large rural area and we see great needs for these kinds of services.

NAME: [illegible]

Senator Pryor,
one thing Velma Hibbert
of Pine Bluff, mentioned - is true
if the government can give
nursing homes $1000.00 of dollars
to take care of our people -
why not give us enough of
that money, so we can take
care of them at home -
there are many other [illegible]
will be ask later