THE PRESIDENTIAL COMMISSION
on the
HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

HEARING ON Financing the Costs of the HIV Epidemic

April 26-27, 1988

August 24, 1988

TO OUR READERS:

The Presidential Commission on the HIV Epidemic held over 45 days of hearings and site visits in preparation for our final report to the President submitted on June 27, 1988. On behalf of the Commission, we hope you will find the contents of this document as helpful in your endeavors as we found it valuable in ours. We wish to thank the hundreds of witnesses and special friends of the Commission who helped us successfully complete these hearings. Many people generously devoted their volunteer time in these efforts, particularly in setting up our site visits, and we want to fully acknowledge their work.

The staff of the Presidential Commission worked around the clock, seven days a week to prepare and coordinate the hearings and finally to edit the transcripts, all the while keeping up with our demanding schedule as well as their other work. In that regard, for this Hearing on Financing the Costs of the HIV Epidemic, we would like to acknowledge the special work of Jackie Knox, Daniel Wartonick and Bert Swift, in putting together the hearing, and Margo Payne and Macy Moy, in editing the transcript so it is readable.

For the really devoted reader, further background information on these hearings is available in the Commission files, as well as the briefing books given to all Commissioners before each hearing. These can be obtained from the National Archives and Records Administration, Washington, D.C. 20408.

One last note--We were only able to print these hearings due to the gracious and tremendous courtesies extended by Secretary Bowen's Executive Office, especially Dolores Klopfer and her staff, Reginald Andrews, Sandra Eubanks and Phyllis Noble.

Sincerely,

Polly L. Gault
Polly L. Gault
Executive Director

Gloria B. Smith
Gloria B. Smith
Administrative Officer

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

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PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

FINANCING THE COSTS OF THE HIV EPIDEMIC

The Hearing was held at the
Interstate Commerce Commission Building
Hearing Room B
12th and Constitution Avenue, N.W.
Washington, D.C.

Tuesday, April 26, 1988

COMMISSION MEMBERS PRESENT:

ADMIRAL JAMES D. WATKINS (Ret.), CHAIRMAN

COLLEEN CONWAY-WELCH, PH.D.

KRISTINE M. GEBBIE, R.N., M.N.

FRANK LILLY, PH.D.

CORY SERVAAS, M.D.

POLLY L. GAULT, EXECUTIVE DIRECTOR

COMMISSION MEMBERS NOT ATTENDING:

JOHN J. CREEDON

THERESA L. CRENSHAW

RICHARD M. DEVOS

JOHN CARDINAL O'CONNOR

BENY J. PRIMM

PENNY PULLEN

WILLIAM B. WALSH, M.D.

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P-R-O-C-E-E-D-I-N-G-S

10:07 a.m.

MS. GAULT: Ladies and gentlemen, members of the President's Commission, distinguished guests, my name is Polly Gault. I am the designated federal official here today, and in that capacity it is my pleasure to declare this meeting open. Mr. Chairman?

OPENING REMARKS

CHAIRMAN WATKINS: Good morning, and welcome to our public hearing to discuss financing the costs of the HIV epidemic. As we'll hear over the next two days, the costs of the epidemic are great in terms of the cost to the individual and the cost to society.

Estimates of lifetime medical care costs to treat an individual with AIDS range from a low of $23,000.00 to a high of $168,000.00. Total costs for loss of productivity from sickness or premature death of persons with AIDS are estimated in the tens of billions of dollars. The costs of human suffering and loss to our society are immeasurable.

The panels testifying today and tomorrow will discuss these costs from their unique perspective, as individuals with the HIV infection, as care providers, as economic analysts, and as representatives of private, state and federal financing sources. These experts are from different geographical locations in the country, close enough to the battle front to understand these issues, but with a broad national perspective for making recommendations.

Issues we will examine will include: how can we better utilize our resources; how can we provide more cost effective care; what are the alternative funding streams; and, how can we find an equitable financing solution to the many costs of the HIV epidemic. We will evaluate options for financing the costs of health care and prevention, which the Commission will consider for inclusion in its final report due on 24 June, 1988.

COSTS TO THE INDIVIDUAL WITH AIDS

CHAIRMAN WATKINS: This morning, we are opening our hearing with testimony from two people with AIDS, who have suffered the economic hardships of this illness, Mr. Larry Ellis and Mr. Kevin Heintz. We would like to commence then with the statement from Mr. Larry Ellis.

MR. ELLIS: Good morning, and thank you for the opportunity to share with you on the subject of the financial costs of being diagnosed with AIDS and living with AIDS. My own case is not dissimilar to the thousands of persons nationally --

CHAIRMAN WATKINS: Mr. Ellis, would you pull that microphone just right up next to you there so we can hear you clearly?

MR. ELLIS: Is that better?

CHAIRMAN WATKINS: That's better.

MR. ELLIS: Okay. My own case is not dissimilar to the thousands of persons nationally who have felt, at the most personal level, the catastrophic financial impact of AIDS. During my hospitalization with pneumocystis carinii pneumonia in February, 1987, my insurance was cancelled by my employer on the guise that I hadn't worked sufficient hours to remain in the group. I had been with the company for four years.

It was necessary to apply for Medicaid to meet bills for hospital, doctors and medications. My personal capital reserve had been wiped out. Shut-off notices had been sent on utility bills, regular monthly accounts fell behind, and the landlord had sent an eviction notice.

At this point, the only thing that kept me afloat was the kindness of friends and limited direct financial assistance from local AIDS charity funds.

But, words cannot express to you the level of tension, stress and frustration operating in my life during this time. I racked my brain for ways to work out the practical details of surviving, keeping a place to live, something to eat, sorting out all the back bills, and, generally, bringing a level of normal back to my life.

Knowing that Social Security disability benefits would take months to come, I applied while still in the hospital and worked out tentative budgets down to the penny to keep body and soul together. I knew that Social Security would not be enough for me to live on, and, again, looked to my friends, without whose help I surely would have lost my mind.

Later on, additional pressure built up because I couldn't work, even though I felt physically able to perform at least part-time work. Social Security requirements that applicants perform no gainful work for the first full year is extremely counter-productive in dealing with the costs of AIDS, both to the individual directly involved and to the relevant local, state and federal social service systems.

Once a diagnosis of AIDS has been confirmed, there is no further doubt about a given amount of disability. Why not let individuals return to as much gainful employment as possible, as soon as possible?

Presently, the system requires that you be made to suffer and become destitute in order to prove that you qualify for not enough to live on.

The same kind of stripping of all stability applies to Medicaid. Spend it down to destitution in order to qualify for meager medical assistance, when in some cases people would fare better if the system allowed them to keep their resources, and jobs, or work, and receive some rounding out benefit.

So, I suggest that a major overhaul of guidelines and regulations governing income from employment, while under consideration for disabled status, be put underway.

Presently, there is a completely negative cash flow from entitlement programs. Cost of entitlement assistance could be cut dramatically and immediately, simply by allowing people to secure work.

With imagination, innovative thinking, strong leadership systems can be changed, or new ones put into place which will allow citizens to receive needed support while remaining a positive force in the tax base. Thank you.

CHAIRMAN WATKINS: Thank you, Mr. Ellis. Mr. Heintz?

MR. HEINTZ: Yes. I'd like to thank you for letting me testify here.

Due to the early symptoms of AIDS, dementia and fatigue, my once thriving business began to slip. Since this was early in the fight against AIDS the symptoms were neither recognized nor treated. As the symptoms progressed my business failed and I was forced to close the doors and file chapter 7 for the corporation and also file personal bankruptcy. Towards the close of the business my symptoms were so severe that routine matters were left unattended. One item that was inadvertently forgotten was regular perusal of mail, and the renewal notice for my health insurance policy was not acted upon. I also, on several occasions, forgot to close the store. The loss of my business was an emotional hardship I was not prepared to bear. With my life now full of anxiety my health began a rapid decline.

The closing of my business came at a cost of $257,000.00 in assets, about $180,000.00 of uncompleted business, and the loss of future profits. Two years later personal losses due to the bankruptcy are still a problem. The IRS has a lien on my home for tax assessment and I have no resources to settle the account. At the time of the bankruptcy I also lost my credit, automobile, my standing in the community, and my confidence.

A month after I closed the business I became so sick that I was unable to even go grocery shopping. I saw a doctor three times before he took a chest x-ray, and he then informed me that he would not be able to treat me and I should look for another physician. I returned to my old physician in Washington and he treated me for PCP, pneumocystis carinii pneumonia. My medical bills for the first bout of PCP were 70 percent paid by Maryland State Medicaid with the balance outstanding. I was not given extended eligibility to Medicaid since my income was $626.00 per month, and Medicaid is cut off after $470.00. In order to qualify for further Medicaid I have to accumulate $1,500.00 in claimable medical expenses every six months. This process is called a spend down and has no consideration for honest ability to fulfill these debts. Several months later, I returned to the emergency room with my second bout of PCP. The hospital called my physician who told them that since I was on Medicaid he would no longer treat me. After fourteen hours of trying to find a physician who would accept Medicaid I was admitted to the hospital under general care without a physician.

During the five months between my initial disability and eligibility for Social Security disability payments, I had no income. My SSD award is $626.00 per month. I collect $79.00 per month in food stamps and receive energy assistance in the winter months which last year amounted to $240.00. My home maintenance costs are minimal because I live in a low-income area. I have no leisure expenses. My monthly expenses are mortgage, $610.00, electricity, $45.00, cooking gas, $18.00, heating averages $70.00, transportation to medical care, $80.00, and telephone, $40.00. Despite the fact that the telephone affords a necessary link with medical care and family support. C&P has no provision for the disabled. These costs total $863.00 per months, $237.00 more than my income.

At the time my illness began, AZT was not approved and was not available for anyone who had PCP. My physician told me nothing helps, and your life expectancy is six months. This was substantiated by five other physicians.

I am not willing to die without a fight. I went to the library to read medical journals, contacted other PWAs, and subscribed to several treatment newsletters. I discovered that about 15 percent of PWAs are surviving because they refuse to accept the medical profession's "nothing" treatment. At the time, the three most common alternative treatments were meditation/visualization, Isoprinosine, and Ribavirin. Meditation was readily accepted although never prescribed. Isoprinosine received heavy criticism among the medical community which made it very difficult to obtain, causing most PWAs to stop taking it. Three and a half years later, Isoprinosine is the subject of research and, provided FDA approval results, will be available in the fight to save lives. In the meantime, many who have been denied it have died. Ribavirin has not shown any real promise in the treatment of AIDS. Ribavirin has shown less toxicity than many treatments tested at NIH.

By continuing my research, I found medications I could combine to both inhibit the virus and stimulate the immune system. Some of these drugs I can get in the U.S., but others have to be bought from overseas through other channels. Since I have been on this combination, I feel better than I have in two years, and my blood count has stabilized. The drugs obtained from overseas cannot be tested by the FDA for treatment of AIDS until they have been tested for toxicity. This takes about 18 months.

The costs of these alternative medications vary but the channels which bring them to the PWA are all non or low profit. My current cost for alternative drugs is $525.00 per month, which is paid by friends and memorial funds. The combined cost of these drugs is less than the cost of AZT.

If the treatment of AIDS remains unattended then America will continue to experience its own Holocaust.

CHAIRMAN WATKINS: Thank you very much, Mr. Heintz, and we appreciate the great detail that you put into your statement. I think those numbers will be valuable to us.

Let me start the questioning this morning, and then I'd like to move over to my left to Dr. Lee. I'd like to focus on spend down a little bit. It's a fascinating area to me, and one that I think is very critical to the issue of Medicaid, because there seems to a ring of unfairness. I'd like to know a little bit more.

If you would take your own situation, Mr. Heintz, for example, and you were to sit back as an objective observer and say, what would have been fair in dealing with you, vis-à-vis Medicaid, getting down to the point where you were justified to apply? What would have been a fair formula, in your own mind? Have you done any thinking, looking at the fact that a change would also impact other diseases, how Medicaid was applied? Is there a fairer formula that can be worked out, depending on circumstances of individuals that would make more sense than the current spend down, go into bankruptcy, poverty and so forth, to be able to even get the funds that are still inadequate to survive? Could you give me any ideas about that?

MR. HEINTZ: Sure.

CHAIRMAN WATKINS: Take your particular case and look back at it.

MR. HEINTZ: In the area of spend down, and what's available through the Medicaid, the cut-off point for the amount of finances that you can earn is set at an amount of money that is far below what anyone could actually live on today. There is no way possible. Look at the costs for rents for a studio apartment in this city, and you are talking more money for rent than what the Medicaid allows you to even make before they will activate medical care.

Rather than basing the Medicaid benefits on the actual amount of finances that the person is receiving, draw a correlation between the finances that the person is receiving and the honest costs of existence in the community that person is living.

There is no consideration for many of the very important aspects of life, particularly, when you have a medical problem, you have to have a telephone. But, those costs are not counted against the different costs that the Medicaid issue considers. They only consider income. It is purely looked at, income and resources that you might have. So, you don't have any resources.

Now, I do a spend down. With that spend down, I have to accumulate the difference between the cut-off of Medicaid and what my income is, and bills for the total length of time that Medicaid will be effective. For me, that's $1,500.00.

Now, I do not have $1,500.00 to spend on the first month of my eligibility for Medicaid, but yet, I have to accumulate the bills for that time period. The way it is written on the Medicaid laws, it is physically, totally impossible to pay the bills that are necessary. It is a forced accumulation of debt with no means of payment. And, that's not only not fair, it's also not fair to the medical community.

If I go in the hospital starting May 1, I have absolutely no way to pay for that bill until it has gone in excess of $1,500.00, and there is no way to pay that $1,500.00. But, that $1,500.00 has to be accumulated prior to Medicaid kicking in and paying what is then the balance.

CHAIRMAN WATKINS: Mr. Ellis, do you have anything to add? Have you taken a look at your own situation and this particular focus on spend down as to what you would do in your case to have generated a fairer formula and relationship between survival, living you might say, and what you were able to achieve through Medicaid?

MR. ELLIS: Well, I think that Kevin has spoken to the question. If you do not have friends or access to some funds, some charity, some form of direct assistance to survive, you will simply cease to exist. Current regulations are a Catch-22. The system is there to serve you, yes, once you qualify into it, but what it puts you through to qualify to its standards, that, in and of itself, is detrimental to your health.

There is an assumption that we're missing, I think, also, is that once you've got Medicaid your problems are solved. That isn't so. Physicians are not required to see you in the District, right here in Washington, 60 percent of D.C. Medicaid is concentrated in one medical practice, in an office of two physicians, because other physicians have either saturated themselves and will accept no more, or they simply don't want to treat people who have to pay by Medicaid. That's $14.00 for an office visit in the District.

So, getting Medicaid doesn't solve your problems. Your fight is not through, in terms of maintaining a good standard of health care.

I'm simply lucky. I just have good doctors who take care of me, so I'm not here to advocate for Larry Ellis. I'm speaking to all those who don't my good luck, and maybe some of the good luck Kevin has had. But, I think that both of us are here today, as well as we are, just because we're lucky, not because Medicaid worked for us, or any of the other systems out there to which I applied.

The problem simply is that, if you have X numbers of dollars in an account, or you have assets that can be liquidated easily, you have to use all of that up in order to entitle. I say, let the individual keep as much of their financial independence as possible, and give them something to boost it, rather than stripping them of whatever cash reserve they may have, assets they may have. I believe that they will live longer in a better state of health and general quality of life if they are able to keep their assets, rather than having them all stripped away to simply qualify for not enough.

CHAIRMAN WATKINS: So, would you agree with Mr. Heintz there should be some indexing to some sort of a cost of living standard, rather than a fixed income concept?

MR. ELLIS: No question.

CHAIRMAN WATKINS: And also, some sort of a more graduated spend down concept that would give you some potential to survive over a period of time --

MR. ELLIS: Yes.

CHAIRMAN WATKINS: -- with the resources you have, coupled with some support, some underpinnings.

MR. ELLIS: Exactly. I think that a person will fare better if they have resources. Let's look at the population who had AIDS who have some degree of resources, that they'll simply do better if they're allowed to maintain that rather than having it snatched away. And, there is no housing if you lose your apartment.

CHAIRMAN WATKINS: Is it your feeling that somebody pays the bill anyway, at some point, someone other than you? In other words, if you cannot pay the bill, somebody else is paying that bill, the government, for example, eventually, or some hospital that has to pick up unpaid bills? Does somebody pay it, or is it just that the health care doesn't get delivered at all?

MR. ELLIS: Some of both. The assumption that people are getting health care is incorrect. There are a lot of people who need health care in this country and don't receive it, AIDS aside, and the problem is complicated by AIDS.

But, some of both. People don't necessarily get health care, and when it is delivered, normally the bill is picked up somewhere along the line, either by the charity fund in the hospital itself, or if the doctor is connected with such a fund to relieve some of that financial load by Medicaid. People are living longer, so you are going to see this occur in Medicare, which raises a host of other questions, because of the SSDI benefits, you are then expected to pay a part of your prescription and a part of your health care, and that benefit already is not enough to survive on.

So, it gets very complicated, and it is burdensome to the individual who is trying to live under this circumstance, and certainly to the system.

CHAIRMAN WATKINS: Thank you. Dr. Lee?

DR.LEE: Mr. Chairman, could you elaborate a little bit on what scheme you are driving at?

CHAIRMAN WATKINS: I'm not really driving at any scheme, but I'm trying to get some ideas, because we've heard this from many of the persons with AIDS who have come before the Commission. I was trying to get in mind some concept that they may have that would make Medicaid work better, more human and more reasonable. I'm just trying to elicit from their point of view, because they've been through it, and they gave us a lot of data.

DR.LEE: I work at a hospital in New York City, Memorial. If you come in, there is no consideration whether you are going to be accepted as to how much money you have, really.

You come in, and if you don't have any money, the social workers get you set up with Medicaid.

Now, what you are driving at, as I understand it, are the people on the whole, who have a little money, who don't want to spend it all before they get into Medicaid. Is that right? What group that slips through are you talking about then?

MR. HEINTZ: Well, the costs of AIDS are not limited to only the hospital visit. The cost of dealing with AIDS is very high-cost medical care that continues far beyond the hospital visit, and starts long before the hospital visit. That is where the main source of the problem comes from.

If you have a prescription, the antibiotics I take cost anywhere from $70.00, $80.00, $90.00 per shot. Now --

DR.LEE: But, Medicaid pays for that.

MR. HEINTZ: If I'm not on the spend down time period. If I'm on a spend down time period, I have $626.00 for the month to live on. During that month, say I have $400.00 worth of prescriptions and office visits that I have to deal with. That leaves me $226.00 to pay my rent, my mortgage, but not counting utilities or anything.

DR.LEE: But the hospital, at least doesn't make you pay that. You just run that up, you are eligible for Medicaid --

MR. HEINTZ: Hospitals are the only ones that do that. What do we do about prescriptions? What do we do about our doctors' visits? What do we do about any other form of medical costs that comes up? The ideal way to deal with the spend down, and the way that the system works, is to go to the hospital and let that $1,500.00, or whatever your spend down amount is, accumulate, and then you start getting collection notices once a week in the mail hounding you for the payment from the hospital. That really is very good for my emotional state.

DR.LEE: Now, you are talking about going to the clinic. I'm not talking about in, I'm talking about outpatient.

MR. HEINTZ: Outpatient clinics are really -- you know, that's great if I have an association with an outpatient clinic. But, quite honestly, the outpatient clinics only treat me with verbal -- you know, a pat on the back. I don't qualify for AZT, because my blood counts are too low, and there is absolutely nothing the clinics will do for me. I go to personal, private physicians that work with me and take a little risk in trying to treat me. Clinics are useless at this stage.

DR.LEE: Well, some clinics may be, certainly not our's.

MR. HEINTZ: All of them in this city are.

DR.LEE: All of them in New York City are?

MR. HEINTZ: In this city, Washington, D.C. I am not familiar with the clinics in New York. I do know that the main treatment clinics in this city, mainly speaking of George Washington University Hospital and Georgetown Hospital, both have such a conservative approach that the things -- that the only thing that is used to treat AIDS is AZT.

DR.LEE: Well, let me drop that one. Let me ask you another question. If the waiting period for Medicare was dropped, would that solve the problem?

MR. HEINTZ: How would I pay for my prescriptions?

DR.LEE: Medicare --

MR. HEINTZ: Does not pay for prescriptions.

DR.LEE: -- Dr. Boufford, doesn't Medicare pay for -- no outpatient coverage on Medicare at all.

MR. HEINTZ: Correct.

DR.LEE: Okay. I'll pass.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: I'd just like a little bit more in the way of detail about the $525.00 a month worth of alternative drugs that you acquire.

MR. HEINTZ: You are asking detail or --

DR. LILLY: Just, roughly, what does this consist of? How much goes to each drug and so forth?

MR. HEINTZ: I'm paying a little over $200.00 a month for the Salk Polio vaccine which I inject into myself three times a week. That is probably the most effective alternative I've been on, and that showed a tremendous change in my energy level. I've been on it for five months now, and it is paid by a memorial fund which I have connections with out of Baltimore. I also am experimenting with Dextran Sulfate out of Japan. It has shown some very strong benefits in stabilizing my blood count. By the way, my blood is monitored weekly through all of this.

DR. LILLY: Who does that, or what type person?

MR. HEINTZ: My personal physician.

DR. LILLY: A private physician.

MR. HEINTZ: Yes. I don't believe that anyone should do this type of experimentation without letting his physician know. I take the Dextran Sulfate, and it, in combination with very low doses of AZT, has shown very strong evidence in stabilizing the drop of my blood count.

DR. LILLY: You are taking the low doses of AZT?

MR. HEINTZ: I'm taking quarter doses of AZT. And, I've been on that for six months now. My white count continued to drop the entire time I was on that, until I added in the Dextran Sulfate. At that point, my blood stopped dropping and actually --

DR. LILLY: So, that's it for what you are actually taking now, or is it?

MR. HEINTZ: No. I am also taking a high dose of Acyclovir.

DR. LILLY: Of what?

MR. HEINTZ: High dose of Zovirax.

DR. LILLY: Okay.

MR. HEINTZ: I'm also taking very high doses of that.

DR. LILLY: Okay. Now, much of what you are taking then is experimental, right?

MR. HEINTZ: Correct.

DR. LILLY: And unproven. So, I'm very sympathetic with the desire to do something.

MR. HEINTZ: Yes.

DR. LILLY: On the other hand, I see difficulties in trying to get a health insurance set-up, such as Medicaid, Medicare, et cetera, to finance that type of experimentation. In essence, self-experimentation. You are the one who is directing that therapy, right?

MR. HEINTZ: Correct, and I do understand what you are saying, and I do agree with you to a limited context. However, if the system was taking a more honest look at medications and trying to get those experimentation medications to AIDS patients through other channels, that would not be necessary.

But, anyone that has a white count that is an obvious AIDS white count, a low white count --

DR. LILLY: Yes.

MR. HEINTZ: -- is not eligible for protocols, and then, if you have a low white count, you are also not eligible for AZT. So, what do you do?

DR. LILLY: I don't have the answer to that. I wish I did.

MR. HEINTZ: If there was a way for people to participate in these protocols under an organized fashion, it would be one thing, and this underground network for treatment would not be necessary.

But, under the current restrictions that the FDA has, grant approval and drug protocol approval takes so long, and it seems that the more promising ones are the ones that never seem to get up there to the actual process.

DR. LILLY: Thank you.

CHAIRMAN WATKINS: MRs. Gebbie?

MRS. GEBBIE: First, just a clarification, Mr. Ellis. I think I was following another train of thought when you said something about your cancellation of your insurance. Was it cancelled in connection with loss of a job because you were too ill, or were you still working and lost your insurance for some other reason?

MR. ELLIS: Well, I don't know what my employer or former employer would tell you if they were sitting here, but it was cancelled because they saw all the potential of -- well, Prudential is the insurance company involved. I'm not necessarily the friend of insurance companies, but Prudential didn't cancel me, the employer did. And, I think that was simply out of fear of seeing a great medical bill develop for me. And, they certainly had to know it was AIDS related, and the typical hysteria, they just wanted out, not knowing what I would do, or assuming that I'd be dead in a few weeks. They tried to get away with a fast one and cancelled the insurance while I was in the hospital.

MRS. GEBBIE: But, while you were still on the payroll of your employer, through whom you had purchased the insurance?

MR. ELLIS: Oh, yes, absolutely. I was not terminated, or fired, and had not quit. I had become ill and was admitted to the hospital. So, I was still technically employed. I was in the hospital with pneumocystis, and it was at that time that the hospital social worker, or someone from their business office, came into the room and announced that my insurance had been cancelled.

MRS. GEBBIE: Thank you for clarifying that. We have heard, and I have heard in a number of settings, that group purchased insurance, as long as one is still employed, generally remains available, and you, obviously, give us an example of how that does not always happen.

MR. ELLIS: Well, technically, it does. If the employer, and sometimes the insurance company, think that you are naive, or that you won't sue, or that you won't pursue the matter, then there are a lot of things people will try to get away with. They guess at what your reaction is going to be.

I was not through with the employer and had some things that I wanted to do with them, so I decided not to sue, even though I had certainly every opportunity to, and many, many people encouraged me to do so, but I didn't for other reasons.

MRS. GEBBIE: You two have both shown a good deal of perseverance and ingenuity in stretching the resources you have available and trying to make the system work for you.

Do either of you, through your various contacts, have any sense of either what number of what proportion of persons ill with this infection simply do not seek any care at all during the intervals between such acute illness that they end up in a hospital without any coverage at all? Do you have any sense of how many folks just say, the heck with the whole system?

MR. ELLIS: Information that reaches us in the National Association of People with AIDS, I would say at least a full one quarter, if not more, of those diagnosed now basically got to health care too late to enjoy a lengthy survival with HIV.

These are generally poor people, people who are under-educated, not accustomed to doctors, or simply don't know how to use the system. It requires great perseverance to get Social Security, to get Medicaid, to get food stamps. The attitude of social workers, and we've done a lot of sensitizing and training around that issue in various departments of governments and cities, it's really unbelievable. I wish you could make yourselves invisible and go to any of these intake offices on any day of the week and see how clients are treated, the misinformation, half information and a very dizzy person leaves there not knowing what he or she has accomplished or what they are supposed to do next.

In the District, other large cities, Houston, the West Coast, most indigent whites, blacks, Latinos, get to the hospital too late and they simply die. Two weeks ago I had to stand in the emergency room at D.C. General and raise high holy hell to get a man admitted who was dying of Wasting Away Syndrome, and they rehydrated him. After we left, they called his family and said, come and pick him up, so I had to go right back and do the same thing first thing Monday morning, threatening lawsuits, and finally the man was admitted and kept for nearly two weeks and stabilized.

This is not uncommon and it is just not in Washington, it's everywhere. It depends on who you are, how well connected you are, who you know, whether you know how to work the system, as to how you survive with AIDs or any other condition.

If you are the average person who is relying on the concern of employees in a social service agency to advocate for you and tell you what you can do, then you are going to die. It's just that simple, and those are facts.

MRS. GEBBIE: Do you agree with Mr. Ellis' estimate that roughly a quarter of ill individuals are just not getting care?

MR. HEINTZ: Yes, I would agree with that.

MRS. GEBBIE: Okay.

MR. HEINTZ: I have a personal friend who has been trying to get on Social Security disability for about a year and a half now. The fatal mistake that was made was that his case of pneumocystis was caught early. He didn't go into the hospital, and it was treated via prescriptions out of the doctor's office. He got over it quite well and is doing pretty well. However, Social Security disability requires that you be hospitalized with pneumocystis, and that you have a bronchial examination to qualify for SSDI. If you don't have that, you don't qualify. This person still does not have SSDI.

MRS. GEBBIE: Does this person have a diagnosis of AIDS, or --

MR. HEINTZ: Has for a year and a half.

MRS. GEBBIE: It is my understanding that that is a presumptive enrollment, regardless of the method of treatment.

MR. HEINTZ: Theoretically, yes, but not realistically.

MR. ELLIS: The payment for SSI, supplemental security income, would be presumptive for three months. It stretches to a total of five months, which gets a little complicated. But, SSDI is a different matter. There would have to be a diagnosis of frank AIDS, and there would have to have been one episode of pneumocystis pneumonia and a hospitalization should be involved in that for the best result in terms of entitling the person to SSDI.

MRS. GEBBIE: I hope my memory is not faulty. Not many months ago we had representatives of that agency in front of us, and in answer to our questions, I think they were very explicit that the physician's diagnosis was critical, not the method by which it had been treated. So --

MR. HEINTZ: Not in the reality.

MRS. GEBBIE: -- I may do some follow up on what sounds like --

MR. ELLIS: That is not true --

MRS. GEBBIE: -- contradictory policy.

MR. ELLIS: -- in the reality. We entitle people in Social Security every day, and the number of lab reports, bronchoscopy reports, proof of Kaposi's, whatever, it's exhausted. In fact, if you apply for SSI and SSDI, with all the necessary supporting documents, you will have 28 different pieces of paper, and much of --

MRS. GEBBIE: 28?

MR. ELLIS: -- yes, and much of that is medical proof of what you are advancing on paper.

MRS. GEBBIE: In deference to others, I'll stop at this point.

CHAIRMAN WATKINS: Mr. DeVos?

MR. DeVOS: I salute you for your persistence. Maybe you can confirm for me that on hospital care it is probably okay. It's when you try to maintain your own dignity and take care of yourself that you run into this very difficult problem in maintaining your own lifestyle, and where you live, and your own home. Is there any central agency, any place you can go, private or public, that would then coordinate and aid you in finding your way through this maze? Is there or should there be?

MR. HEINTZ: Not in my community. In the Washington area, and your larger -- most of your larger cities throughout the nation, at the early onset of the disease, the gay community centers pull together and created this, but it is not set up on a general board for AIDS in dealing with in any regards beyond that. And, those community centers are overrun with work right now, because they are taking all members of the community that have the problem, instead of being isolated within their own groups. And, consequently, they are so overrun with AIDS patients and getting no help in that regard, and they do not reach out into the other smaller communities throughout the nation. The Midwest, as was mentioned a minute ago, doesn't have a lot of help.

I lived just down in southern Maryland, and there is no organized force for helping me deal with my individual problems whatsoever. The only thing I have that is available in my community is Maryland State Medicaid. Everything else I have to drive to Washington for.

MR. DeVOS: Well, it just seems like, one thing we can get at is a central point where AIDS patients can go. When you are already sick, it's bad enough to just deal with living without having to fish your way through all the other things. If there was one person who would just work your case through and help you -- you know, part of the goal is to keep you out of a hospital so you can maintain your own life, and live on your own, and I think our goal here is, how do we keep you in a home setting as long as possible? It's certainly a lot cheaper than being in a hospital.

The problem is, the path to the hospital is a lot easier than the path to doing what you are doing, and yet, that's the lower cost way to accommodate you and still give you some dignity. It just seems like we build the obstacles in the wrong place, that's all.

MR. ELLIS: I think you put your finger right on part of the problem, Mr. DeVos. The path to the hospital is the easier road. Dump the problem there, rather than do the things necessary to allow people independent living.

We do have a network in the National Association of People with AIDS, we have 68 affiliates or coalitions in 37 states, representing 8,000 people living with AIDS. Most of them have a social service entitlement component. Lifelink does, the local affiliate here in Washington. We spend most of our time on social service entitlement. The private social service providers, and many of the government agencies, are now basically case dumping on us, simply because we have no other agenda. We don't have the bureaucracy, the layers of internal problems.

When we hear of someone with AIDS who needs help, we get right to that person, sort out what they are entitled to, and speedily get it to them. But, where Kevin is living, in southern Maryland, and in other places around the country, rural or, indeed, in many of the cities still, NAPWA doesn't have a chapter capable of doing this kind of work. There is a major service provider in Washington, D.C., that gets help to many people, but has a lot of problems of its own, and we're beginning to catch their overflow now.

MR. DeVOS: It's just the difference between public and private, that's all.

MR. ELLIS: Yes.

MR. DeVOS: When you go public, there are 42 regulations. Everything has got to be in a book, and you just can't treat it as you would because your heart tells you this is what you ought to do a minute.

MR. ELLIS: Or, go private, and you've got 42 personalities, so it's --

MR. DeVOS: If you can funnel that off to a private group and say, we're going to find sources to help you, whether that's a charitable organization, or a hospital, or, we just look it up in our book and say, call this number and we'll get something done. That isn't the way it works on the other side. But, I appreciate the insight into that, and I appreciate your willingness to fight your battle and want to maintain your own dignity in the process, and I think it's an important road for us to try to open for you and ease up on.

CHAIRMAN WATKINS: Before I go to Dr. Conway-Welch, let me just follow-up on what Mr. DeVos said. It seems to me that any time you get into a large bureaucracy, it seems to always hurt the little people, many of whom don't want to sue, don't want to take on the burden, in fact, don't even know how to do it.

Now, you've mentioned that. It seems to me that that's almost a first step that needs to be cleared up before we really know where we stand on lots of other things. If we don't clean up our own system and have it operate effectively for the people that need it most, when the system is really there but not known, we aren't helping the individual.

So, I guess what I'm hearing out of this, perhaps, is something that might go this way. There is a protection and advocacy system for the handicapped. They do the intervention, so lawsuits aren't necessary. Is there merit to including those afflicted with the HIV under that system, to make sure we seek those with HIV to come forward so we can explain what's there for their optimum health care.

I really do believe that in the long run by doing that, we will tend to give some credibility to the system, that we're interested in the human being at the end of the string, not interested in setting up a bureaucracy.

So, would you suggest we take a look at the Protection and Advocacy system to include those with HIV, and make it much more aggressive? Let's have a demonstration project so that those afflicted are willing to come forward and say, I need help, I don't know where to go, this is where I stand financially, are there things available and can recommendations be made so I can stay at home, where it is the least cost to me or to others. Would something like that be attractive to you?

MR. HEINTZ: My initial response is no, because of the aggression, the forced recognition. You are already dealing with people that have been humiliated, shoved, have lost confidence in the system, are fearful of confidentiality, and you are going to respond to them with an aggressive fashion. You will force them deeper into the bushes.

You need to deal with them on a much more compassionate level, and offer some of the things that you are talking about in regards to education of how to work with the system. But, an aggressive stance in this regard, in trying to flush the bushes, is going to send a great deal of panic and fear in many people, and it is not the means to deal with people that are suffering from an illness.

CHAIRMAN WATKINS: What I meant by my comments is not going out and flushing the bushes aggressively, but rather, to flush the system aggressively so that people come out of hiding and come forward and say, that's the kind of advocacy I need to help me. That's what I meant by flushing the bushes, not by stirring up those with AIDS, but stirring up the bureaucracy so that the people with AIDS can come forward. They would now have an advocate in their behalf to help them through the bureaucratic maze that sits out in front of them, that they just are incapable of dealing with because they don't even know what exists for them.

MR. ELLIS: I would agree with that as you just stated it. I call all of this the system. The system has to be there in a very responsive way to say we recognize the problem, and these are the things that at the federal level of government we are geared up to do now, these are changes that we can make in state regulations, as services trickle down.

Much of the problem is that Medicaid is a discretionary fund of money. Medicaid in the District is not the same as Medicaid right across the river in Virginia, or in Maryland, or in Texas, or in Mississippi, or in Arizona, where they don't even call it Medicaid, they call it Access. And, because this is discretionary, and the general federal guidelines of how these monies can be used are specific and yet vague, at the state level Medicaid administrators can administratively literally write out individuals or groups or populations of people they don't want to serve.

In Texas, they've been changing a lot of their regulations lately, but I think I'm still correct, a single male in Texas cannot entitled to Medicaid. In Virginia, the AZT Payment Assistance Program, until the 14th of this month, you couldn't qualify unless you had a diagnosis of frank AIDS. They liberalized it now to include people who are ARCish. But still, if you have any co-pay insurance for prescriptions, you don't qualify.

When federal monies are made available, and programs established, there must be continuity. We have 50 states with 50 different interpretations on how to use this AZT money. Here in the District, effective January 1, the program was restructured to include people, because the regulations were so ridiculous, no one could access it. Virginia just modified their program some, but you still can't get into it, and we have many people, many people walking around with prescriptions for AZT who cannot get it paid. And, they have insurance, many of them, and it is working against them. It's that kind of thing the federal government can do. It can say, here's the money, but here are the uniform regulations to entitle the people it's happening to.

CHAIRMAN WATKINS: Thank you, Mr. Ellis. Dr. Conway-Welch?

DR. CONWAY-WELCH: Just a couple of quick questions. I think I know the answer to this, but let me clarify. With SSI and SSDI support, the diagnosis of frank AIDS is required, and that does not recognize any of the ARC syndromes at this point, is that correct, or still correct? I'm seeing two different answers. Help me out.

MR. ELLIS: It is correct. What we often have to do is build a case. A person will call and will say, I've got this condition, I've got that condition. Now, I know it all adds up to this person having AIDS, but when it comes down to the person reviewing the application at Social Security, they are paid to find the proof. They are not paid to entitle people who don't meet guidelines. So, we have to prove as much AIDS as possible.

But still, you need a diagnosis of AIDS, and because CDC broadened its definitions doesn't mean that Social Security has to follow that. They've been pretty liberal so far in their interpretation, but they don't have to recognize everything that CDC calls AIDS.

DR. CONWAY-WELCH: So, the Social Security Administration does not necessarily recognize CDC's different or newer --

MR. ELLIS: For the most part, they do, but they reserve the right on a case-by-case basis to say to the applicant, prove frank AIDS. That's why we try to go in with the initial applications, the whole packet, proving as much AIDS as possible, so that the application doesn't become challenged along the way.

From the initial intake, it goes to the Determinations Unit, where, based on the medical proofs provided, the hospital reports, the doctor's reports, all of that, a decision is made by Social Security's doctor whether, in fact, we have a disability based on a diagnosis of AIDS. So, as much as we can have in that folder when it gets to the Social Security doctor's desk, the better, the more likely we will get a ruling of disability.

DR. CONWAY-WELCH: Your statement that "you have to prove as much AIDS as possible" is incredible. I understand what you are saying, but I certainly think I can foresee the problems that patients would have.

One last question. Mr. Heintz has shared some of his drug therapy with us. In your experience what are the more common experimental self-monitored medications that patients are using?

MR. ELLIS: Well, I know a lot of people who are doing things similar to what Kevin is doing. AL 721 has gotten kind of old, but people are still using AL 721. NIAID, National Institutes of Allergy and Infectious Diseases, has finally brought that into their study group, I believe. Earlier this year, in January or February, I was up there and they announced that.

But, it's a little late in the day, and, again, I don't know that it's going to help for them to study that now. People have been doing it for a long time. People want to live. They are frightened. Only 40 percent of those who began AZT have a good benefit from it, long term. I've been on the drug for over a year, and, in fact, this week I've decided to reduce my dose to half, and increase the amount of Acyclovir I take. A year of AZT is a long time at a full dose, and I've just made the decision to reduce that amount because of the problems with the drug.

I, basically, follow a Western medicine model, AZT, Acyclovir and Naltrexone Syrup. Naltrexone is, simply stated, it's an immune system modulator in low doses related to HIV infection. That's what I do personally, but I'm changing that also. I think I may increase the amount of Naltrexone, step up the amount of Acyclovir and decrease the amount of AZT. I make these decisions for myself. I don't allow doctors to think or decide anything for me. Their role is to be advisors, and that's as far as I let them go.

DR. CONWAY-WELCH: Thank you, Mr. Ellis.

MR. HEINTZ: Can I add one thing? Mr. Ellis was talking a minute ago about AL 721, and that it is just now entering the research realm.

I was speaking earlier with Mr. Lilly about the onset of getting further research on some of these alternative treatments more rapidly. AL 721 was introduced into the alternative network in September of 1983, through the Lancet Medical Journal publication. Just now it is entering into research in the United States, five years later.

CHAIRMAN WATKINS: I have two quick follow-ups, Dr. Lee first, and then Mrs. Gebbie.

DR.LEE: We have heard Medicare waiving the eligibility time period would be an excellent answer. You don't think so. Medicaid, the qualifications surrounding Medicaid are not satisfactory. If we had socialized medicine, you certainly wouldn't be able to go and find your private docs and your medications that you want. Tell us what you want. How would you amend the system?

MR. HEINTZ: As I see in dealing with the current problem we have in regards to the AIDS epidemic, if we look at some of the past ways that we have dealt with epidemics in this country, for example, the polio epidemic, that was a very effective means to pay for the definite needed medical expenses, all associated expenses. There was a foundation established that charged the polio patients $20.00, one-time fee. From that point forward, all medical care, prescriptions, braces, therapy, hospital care, home care was paid for by these foundations.

DR.LEE: So, philanthropy would be your number one choice.

CHAIRMAN WATKINS: Mrs. Gebbie?

MRS. GEBBIE: Although I think there is something to be explored in that philanthropic model, I'm not certain that everyone who had polio in those days got care for $20.00 from what I've heard. My question is to explore just one little bit further the issue of discrimination, not because of HIV infection, but because of paying your bill with Medicaid.

I think both of you described experiences in which even during periods when you were covered you didn't get care, and I have some concern about holding out coverage of Medicaid as being an answer, because, in fact, I hear from people who are covered by Medicaid because they are single women with children, or because they are elderly people, that they can't get in the door because of the kind of card they are carrying to pay their bill.

Have you done any exploration of that? Have you differentiated what might be discrimination based on the source of payment as opposed to the kind of disease you have?

MR. ELLIS: Well, we haven't investigated it, but we see all kinds of social problems. There is, indeed, a discrimination, racially, there is a discrimination based on the kind of disease you've got, there is discrimination through elitism. It goes on. It really boils down to a case-by-case, individual-to-individual situation.

When someone comes to our coalition office, and they are trying to get entitled, or they've got problems, whether it's an infected mother, or a single male or whatever, we have to listen to what they are individually experiencing and find out what we can entitle that individual to.

We are thinking too much on how to service groups, and we're getting away from the needs of individuals, and they vary, they vary greatly. There is a young man 18 years old sleeping on my hideaway sofa in my living room right now because he was thrown out of a housing program because he tested HIV positive. There is no housing program anywhere in the country to accommodate HIV-infected teenagers. I don't know how long he can continue to live with me, but the system has nothing for him.

We hear these kinds of stories all of the time. We deal with people with incredible problems all of the time, who have been neglected by the system. There are many, many areas. There are nine distinct areas where in the United States we've not responded to housing for people affected, and anywhere in the range of HIV, and I don't mean acute care in a hospital, I mean the time in between. That's where it really gets touch and go. What if someone slips into dementia. What about the home care, the visiting nurse kind of situation, that kind of housing we need.

I'm capable of independent living, but that could change at any time. If it weren't for a good base of friends, I would be just one more statistic that the system has not really designed -- what you were getting at before about a clearing house, this is where you can go, this is what's there. And, once that is really done in a federal way, and the guidelines and the standards are uniform for all of the states, counties and localities, only then have we responded to this. And, this can be the catalyst to address all of the social ills.

AIDS is a great opportunity if we use it that way. There is a great silver lining in this black cloud if we would look at it and recognize that and use this as a catalyst to change a lot of things.

We could actually solve problems, rather than putting patches on them constantly. One thing, I would just like to throw this out, if you'll allow us just a few more minutes, and that's the waiting period to go back to work. One of my pet peeves is that we've got a negative cash flow from social service entitlement, because you are telling people that you must be disabled, sit at home and watch soap operas for a full year, when you might, indeed, be able, physically able to go back to work. But, if you do that above the table, you are jeopardizing your Social Security disability application, because if you are disabled how are you able to work?

So, you live on this SSI, which, in most places, is about $350.00 or $380.00 a month, it does vary state to state because there is a state matching contribution to the federal amount. Let's waive this waiting period, acknowledge the person as disabled, give them their benefit. It's not going to be much anyway, because this is hitting people at a young age, they've not paid into the Social Security base, so their checks are going to average about $400.00 a month. Let them go back to work, so it's not all outgo from the Treasury, you've got an individual back on the job, paying something back into the tax base, in effect, paying his or her own way, those who are capable of it.

And yet, if a person is weak and is unable to work, then let the system have compassion and provide their benefit. But, I actually could not work, even though I was able to, in order to protect the $476.00 a month that I had to wait five months to get, and had to be disabled for a full year before I could return to any legitimate work. You are fostering an underground economy here. You are making people go under the table to get matching monies or enough money to go with their Social Security check, their SSI check, to live on. If I didn't have friends who were well off, if I weren't lucky in many respects, I would not have survived, and I have many friends who simply carry me. It's that simple. I have good friends who take care of me, because on $476.00 a month I could not live. My friends have been remarkable, wonderful, and it just depresses me when I see the kind of need that I see, and people who don't have well off friends who can help them, as mine have helped me.

The last thing you want to do is lose your place to live. That worried me, that worried me more than anything else, was losing my place to live. I have seen the group housing, and I have seen the so-called supportive settings that many service providers set up in their housing programs. And, if you are willing to chuck your soul and all of your independence and freedom out the door, then you can live in these housing programs. But, if you are an independent person, if you have some dignity about you, and you intend to remain in charge of your own life, then they don't really want to see you, many of these AIDS service providers, because, basically, they want to own you to perpetuate their own empires and bureaucracies.

Let people work, I really ask that. Let's change Social Security. Let's let people go back to work. Let's sensitize employers, get them to hire people. If you are not sharing needles in the work place, and having sex, there is no risk, we all know that. Let people get back into the tax base.

MR. HEINTZ: I agree with that fully.

CHAIRMAN WATKINS: Well, we thank you both very much for coming to the Commission today. It's been very useful to us, and this particular set of hearings is focused on finance, but clearly, we are in that business because what you are talking about here are some cost offsets, which if they worked, the total system would pay less and be more compassionate to the individual. And, I think your cogent, balanced thoughts have been very useful, and I thank you for them.

We may be in communication with you again because you have given us tremendous insight. As you know, we've talked to hundreds of persons with AIDS, and, basically, they are all telling us the same story, but you've put it in very clear terms with some very specific recommendations. We appreciate it. Thank you very much for coming before the Commission.

HIGH COSTS OF INPATIENT HOSPITAL CARE

CHAIRMAN WATKINS: We'll move to the next panel now, High Costs of Inpatient Hospital Care. Dr. Jo Ivey Boufford, President of New York City Health and Hospitals Corporation; Dr. John Burnside, Associate Dean for Clinical Affairs, University of Texas Southwestern Medical Center at Dallas. Also, he's appearing on behalf of the National Association of Public Hospitals. Mr. William H. Johnson, Chief Executive Officer, University of New Mexico Medical Center, and Chairman of the Special Committee on AIDS/HIV Infections Policies, the American Hospital Association. Dr. Robert H. Parrott, Director Emeritus, Children's Hospital Center, Chairman AIDS Task Force, National Association of Children's Hospitals and Related

Institutions, and Mr. Richard N. Yezzo, President of St. Clare's Hospital and Health Center of the Archdiocese of New York. Glad to have you back with us again, Mr. Yezzo.

So, we'll start then on this panel with Dr. Jo Ivey Boufford.

DR. BOUFFORD: Good morning. Admiral Watkins and members of the Commission, we are very pleased to testify before you on the financing of AIDS care.

The New York City Health and Hospitals Corporation, of which I am President, is the largest municipal hospital system in the country, and we care for more people with AIDS than any other single provider in the United States.

Today, as I speak to you, we have over 450 inpatients with AIDS in our 11 acute-care hospital beds, nearly 40 persons with AIDS in our long-term care facilities, and each year are providing ambulatory care to over 2,000 persons with AIDS.

Seventy-five percent of our AIDS patients contracted the virus as a result of IV drug abuse, either as users themselves, sex partners of users, or children of IV drug users.

We believe that the lessons we have learned in our experiences in treating people with AIDS will be increasingly applicable to providers and policymakers throughout the country, because although four years ago, New York City had over 50 percent nationwide of AIDS cases, at this point it is nearer to 30 percent and expected to go down.

Before discussing our specific recommendations, I want to raise three major concepts that we believe have a bearing on the issues of financing of care.

First of all, AIDS is a complex disease. The medical and psycho-social needs require an interdisciplinary approach. Second, patients' conditions are volatile, and they move between levels of care very quickly, so there need to be those linkages between ambulatory care, acute inpatient care, long-term care and home care. Third, managing the disease most effectively requires a primary care approach or case management approach to assure smooth movement and coordination of services.

Needless to say, the U.S. health care financing system is not now a unified system, but rather a patchwork of special programs for certain populations, which really does not lend itself to the level of coordination needed for persons with AIDS.

A second general point is that care for persons with AIDS is costly. In an era of cost containment and DRGs, this creates a disincentive for providers to care for patients whose cost is greater than the reimbursement available.

The cost for persons with AIDS is largely a new one to the health care delivery system. These are, for the most part, people who would not have been in a hospital, or would not have been using the kinds of expensive services they now require. And, from the point of view of municipalities and public providers, in an era of limited resources, new costs and the need for new dollars compete with existing program needs and force us into making very difficult choices for Medicaid dollars, housing resources and hospital services.

Finally, AIDS patients face very real problems of access because of the disease itself, discrimination, fear, the burden on health providers, and because of the cost and the lack of adequate reimbursement. This lack of access is not unique to AIDS patients and affects many individuals needing health services in our country. However, it has been highlighted most dramatically with the AIDS population, and it potentially increases the burden on public providers who historically have stepped in in these kinds of circumstances, and on those municipalities which have a large number of AIDS patients. It underscores the role and responsibility of the federal government in assuring care.

Financing strategies must address the complex array of services and levels of care needed, assure new dollars into the system, and assure equitable financing so that there is equal incentive for all providers to provide services to persons with AIDS, both assuring access and equitable distribution of services.

In the short term, we make the following recommendations for augmenting the current private insurance system and Medicare and Medicaid. First, support for initiatives to address the growing problem of the uninsured, such as S.1265, which requires employers to offer health insurance coverage to all employees who work at least 17-1/2 hours a week; support for Senator Moynihan's bill, which waives the 24-month waiting period that currently prevents a person from AIDS for qualifying for Medicare; establishment of a federal AIDS DRG for Medicare patients that adequately reflects the costs, length of stay and intensity of illness that at least could be a model for state Medicaid programs under the DRG system; increased reimbursement for all patient care to reflect the costs of universal precautions which are increasingly being implemented by hospitals for all patients and costs; increasing the federal Medicaid matching rate for home care; to a minimum of 75 percent for those states that have a comprehensive program for home health care, and finally, expanding the CDC definition of AIDS to encompass the types of care needed by people who have ARC or are HIV infected.

We, in New York City, at HHC, are very pleased with the recommendations of this Commission so far, and are eager to cooperate with you in what may be the most difficult set of recommendations, those involving the financing of services for persons with AIDS. Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Boufford. Dr. Burnside?

DR. BURNSIDE: Good morning, Admiral, and ladies and gentlemen. I'm from the University of Texas Southwestern Medical School in Dallas. Our major teaching hospital is Parkland Hospital, and I'm here to represent that hospital and the National Association of Public Hospitals.

While there is a plethora of tragedies related to HIV infection, your focus this morning are on the financial inequities which befall patients with HIV infections and the institutions which provide care for them.

Similar to some other deadly and disabling diseases, HIV infections result in personal financial disaster. Unlike other diseases, however, we have many instances where the financial devastation occurs as a result of HIV infection but before the manifestation of the disease or the use of the health care settings, such as you've heard this morning of loss of employment and insurance is an all too common result of positive HIV testing.

This pre-illness financial ruin, together with the subsequent high costs of care when the illness begins, leads to disproportionate reliance for care on the public hospitals.

Dr. Androulos of the National Association for Public Hospitals, in a survey of public and private teaching hospitals, found 19 hospitals which were caring for more than 100 patients each in 1985. He further found that of the 169 hospitals he surveyed, they accounted for just 10 percent of the beds, but were accommodating 30 percent of the nation's population with AIDS.

Fifty-four percent of the 5,393 AIDS patients in that year served by these hospitals had Medicaid coverage, while another 24 percent had no insurance, public or private.

In 1985, the total cost estimated for this group of patients was $380 million. While public hospitals are not expected to cover their entire cost from patient care revenues, the discrepancy between the costs and the reimbursements in the care of the AIDS patient is particularly discouraging.

It must also be reemphasized, as Dr. Boufford has commented, that this represents a new case load for public hospitals, and, as such, is added to the already enormous needs of others who are ill and poor.

Inequity is further compounded geographically. Economically disadvantaged states, by definition, have more poor and uninsured citizens. Also by definition, these states have fewer dollars to contribute to this large need.

While the daily inpatient costs of caring for a patient with AIDS is much the same throughout the nation, approximately $630.00 a day in 1985, and about $720.00 a day in 1987-88, the reimbursement for that daily rate in the south is $282.00 a day, and in excess of $500.00 a day everywhere else in the United States.

We feel this very keenly at Parkland Memorial Hospital, a 782-bed facility supported by the taxpayers of Dallas County. On any given 24-hour period in Parkland, 108 patients are admitted, 431 visits to the emergency room, 1,200 patients are seen in the clinics and 40 babies are born.

In our AIDS outpatient clinic, 679 patients are cared for, 436 of whom have AIDS or ARC. The annual costs for AIDS patients at Parkland is $22,000.00, exclusive of costs for AZT, inhalation pentamidine or other drugs. Fully, 75 percent of our patients have no insurance, public or private. A calculated loss of $3 to $4 million in 1987, and these are only the direct costs, they do not include the additional costs of new therapies becoming available, universal precautions in the hospitals, and additional personnel needed.

Our budget projects for '89, which include some of these costs, anticipate an allocation of $11 to $12 million for AIDS at Parkland. Dallas County is struggling. AIDS in Dallas County will probably cost $57 million in 1991. The taxpayers have been supportive. The County Commissioners have been supportive. Lay groups, professionals, private groups have all been supportive. We have a model of case management in the AIDS Arms Network, which is independently funded, with child care, hospice development underway, and the Gay Alliance has an extensive help network.

Simply stated, we have a new disease, a disease which assaults financial resources as surely as it assaults the immune system. This new disease has produced a new group of poor, sick people. The resources are limited, and the need has increased. The waiting line gets longer, not longer just for the AIDS patient but for all who are poor and sick. The line is long in New York, it is long in San Francisco, and even longer in the south.

While we will always have to contend with needs in excess of our resources, surely we can take a national perspective of the scheme of allocation. Establishing national standards of Medicaid eligibility and benefits might accomplish this. Such an action recognizes that the anguish of AIDS is part of a larger breach of justice and equity in the United States.

This is not a call for a massive federal bail-out. The cooperative public, private, national and state efforts must continue and increase, but the wound is too deep for a band-aid. Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Burnside. Mr. Johnson?

MR. JOHNSON: Admiral Watkins, members of the Committee, my name is Bill Johnson. I'm the Chief Executive Officer of the University of New Mexico Hospital, and I serve as the Chairman of the American Hospital Association's Special Committee on AIDS. I am pleased to have this opportunity to share our experience with you and the cost of AIDS and financing AIDS in New Mexico, as well as the recommendations of our AHA committee.

The University of New Mexico Hospital is a 344-bed tertiary teaching hospital located in Albuquerque, New Mexico, and, as such, we have cared for the majority of the AIDS patients in our state, as well as a number from surrounding regions. Our scenario is different from those of my colleagues you just heard from Texas and New York. However, I think may be more representative of many areas of the country in which high prevalence of AIDS is not the same issue as we've talked about before.

To date, the volume of AIDS patients we have served remain relatively manageable. We are currently providing AIDS services to about 27 patients, most of whom are being cared for on an outpatient basis. Critical to our ability to effectively manage our patients has been the development of an alternative care network for individuals with AIDS. Outpatient and community-based services are not only less expensive, but they often represent the most appropriate and compassionate care as well. New Mexico is currently one of only three states with a Section 2176 waiver permitting the state Medicaid program to pay for a broad range of home and community-based services, specifically targeted to individuals with AIDS. Due in large part to this continuum of care and our active outpatient clinic, we've been able to hold the average length of stay for an AIDS patient to only seven days during this first six months of our fiscal year. Consequently, our lifetime inpatient costs are now averaging about $20,000.00 per cases, significantly less than a few years ago.

If the first lesson I have to share with you is that outpatient and community-based services can be cost effective, the second lesson, and you heard this repeatedly this morning, is that these services are not free and do require significant commitment of resources. While the availability of a network of support services significantly reduced the use of expensive inpatient hospital care, there has been a parallel growth in the use -- and thus, the cost of the outpatient care setting.

For example:

- The number of outpatient visits per patient has increased dramatically over the past year. In fiscal year 1987, 27 AIDS patients accounted for 955 outpatient visits to our clinic. In the first eight months of this fiscal year, the same number of patients have already logged in 1,121 visits, more than in the entire previous year.
- The per patient cost of this outpatient care has also risen dramatically -- leaping from $7,800.00 in 1987, to an average of $14,000.00 during the first six months of this year, mainly, in large part, to the introduction of the drug AZT. These figures do not include the growing number of individuals with AIDS-Related Complex (ARC) or HIV infection that are also seeking treatment.

Payment for care rendered varies considerably. Approximately 30 to 40 percent of our AIDS patients at any given time are covered by private insurance. However, anywhere from one-third to one-half of our patients are self-pay. In reality, the vast majority of self-pay are non-paying patients, as they lack the resources for their care. In sharp contrast to many other states, only about 10 to 15 percent of our patients are covered by Medicaid, because in spite of New Mexico's efforts to be responsive through the Medicaid waiver, our basic Medicaid program is so restrictive that many cannot quality for coverage.

As an aside, I note that you will have individuals speaking later in these panels, and recognizing that Medicaid is a state program and it varies dramatically from state to state, it's very difficult to draw generalizations regarding those programs.

But, in New Mexico:

- An individual who qualifies for Medicaid, by virtue of eligibility for SSI, as in the case with most AIDS patients, is permitted to have an income of only a little more than $4,000.00 per year, less than 50 percent of the federal poverty level.

- The categorically needy under AFDC are even worse off; a family of three must be below the 35 percent level of poverty in order to qualify for assistance.

- And, as indicated before about the spend down program, although they are programs that might be offensive to some, they do offer other opportunities, but there are 14 states, including New Mexico, that have no medically needy programs.

Even those who meet the strict eligibility criteria, reimbursement for medical care is very inadequate. On the average in New Mexico, I receive about 32 percent of charges, or lose about $3,000.00 per admission for a Medicaid patient under AIDS.

We have managed to cope with the costs of AIDS care to date because of our relatively small case load and our success in meeting the needs of patients outside the hospital setting, and I think that this is indicative of many, many other settings in which you have a small amounts of AIDS cases where the introduction of AIDS in the community can be absolutely devastating. In the high-prevalence areas, you already have huge resources and systems set up, but in the smaller rural environments where three or four cases are introduced in a community it can be absolutely devastating.

If the number of patients, however, should significantly increase, or if the nature of the patients' needs change dramatically, if we experience an increase in the patients who are IV drug abusers, which we have not had a substantial amount of in New Mexico, or if there are additional cost factors introduced, such as the compliance with the CDC universal precautions, which is a substantial increase in cost to hospitals, or additional therapies that develop, our ability to provide care will be jeopardized.

Moreover, changes in the payer mix may have a dramatic impact. If private insurance continues its retreat from coverage of AIDS care, the burden of uncompensated costs will become unmanageable, and hospitals do not have the resources to absorb the growing burden.

The most important lesson I have to offer is that we must come to grips with the need to develop a continuum of care that is adequately financed or risk being overwhelmed by the problem. AIDS has presented new challenges to us in the health care field, but perhaps more importantly, it has re-illuminated old problems that have eluded resolutions for years -- the emotional, social and financial stresses that can result from catastrophic illness and the worsening problems of medical indigence and inadequate health care insurance coverage. None of these are unique characteristics or byproducts of AIDS, but the rapid escalation of the disease, its particularly savage course, and its current prevalence among younger people in their most productive years have added new dimensions to the challenges of caring for the terminally ill.

The American Hospital Association's Special Committee on AIDS, which I serve as Chairman, has given considerable thought to the complex issues involved in financing care for individuals with HIV-related illness. This panel of experts represents a broad spectrum of experience with the AIDS epidemic, and includes representatives from high-prevalence areas, such as San Francisco, New Jersey and Florida, as well as individuals from medium-sized cities and one from small rural. I've attached a copy of this Committee's recommendation to your report for your further review and information.

A fundamental issue the Committee has grappled with is whether the AIDS care and health coverage for HIV-infected individuals can be addressed adequately within the traditional pluralistic approach to financing health care, or whether a separate public program must be created. Such a determination involves basic philosophical choices that must be made within the context of harsh political realities.

We believe that every effort should be made to assure that care for individuals with AIDS and HIV infection can be addressed under a pluralistic system of private and public funding. Reliance on this pluralistic system allows for targeting finite public resources to those most in need, while distributing the cost burden across a number of payers. Complete transfer of responsibility for AIDS care to a public program would not only shift the costs for those who could afford to pay into an already strained public sector, but would also raise serious questions about the general long-term viability of private insurance as the American health care financing mechanism of choice.

Moreover, the establishment of an AIDS-specific public program would require a large commitment of financial outlay at a time when both state and federal governments are confronting increasing budget deficits. But perhaps even more significantly, expanding public programs only for AIDS would overlook the needs of many others with catastrophic illnesses, such as Alzheimer's disease and terminal cancer, who have encountered similar difficulties in financing a range of needed care. Not only would such a move likely create substantial pressure for public funding among programs for a variety of other illnesses, but it would also permit the weaknesses present in our current insurance and payment system to go unaddressed.

Clearly, if we address AIDS under a pluralistic financing system, we must take actions to preserve the private sector role. Steps that might be taken may include:

* Prohibiting coverage exclusions or significant benefit limitations based on HIV status in small and large group health insurance policies.

* Providing incentives for creative ways to spread risk through new pooling mechanisms, such as multiple employer trusts or state or regional pools to help make affordable coverage available to the general population.

* Encouraging formation of reinsurance programs specifically for AIDS.

* Exploring ways of subsidizing the premiums for the continuation coverage required by the 1986 COBRA Act for individuals who are disabled when they leave employment.

We must also make health coverage available to the unacceptable number of uninsured individuals in this country -- a problem that's being exacerbated by the high cost of AIDS. Some 37 million Americans do not have access to a health care plan, public or private, although 86 percent of these individuals have some connection to the work force, either by direct employment or by being the dependent of someone who is employed. One option the AHA supports is the mandated employer-provided insurance, such as proposed in the recent bill sponsored by Senator Kennedy. We believe that the time has come to make the provision of health care a societal condition of doing business.

Finally, it is clear that many individuals with AIDS will not be able to afford private coverage, even if it is partially subsidized. The growing number of intravenous drug users and poor children with AIDS clearly indicates that, increasingly, adequate public coverage must become available to meet the needs of these patients. Unfortunately, today medicaid covers only about 38 percent of the poor nationwide. Because of state discretion in establishing income thresholds and covered services, the adequacy of Medicaid coverage for the poor widely varies across the country.

For the long term, we believe that Medicaid will require significant restricting if it is to adequately serve the poor. There are a number of options that might be pursued now to greatly improve Medicaid eligibility coverage and reimbursement for individuals with AIDS and other catastrophic illnesses. They are:

- Establishing a minimum national Medicaid eligibility floor set at 50 percent of poverty, with a phased-in plan for moving to 100 percent of the poverty level.
- Adopting a medically needy program in all states. Fourteen states, including New Mexico, still do not use this option.
- Allowing states to establish higher income thresholds under the medically needy program, thereby enabling them to serve a greater percentage of the poor while accessing federal dollars. Currently, a state is prohibited from setting its medically needy threshold at a level greater than 133 percent of its AFDC payment. In most states, the AFDC payment level is abysmally low.
- Giving states the option of further raising the income threshold for the disabled, so that they will have more flexibility in targeting their dollars.

In addition to improved Medicaid eligibility, the scope of covered medical services is a very important issue for AIDS patients. Although expensive hospital care is often covered, many of the support services that would allow treatment in the community or at home are not.

One of the components critical to both the quality and effectiveness of care for AIDS patients is case management. Congress recently gave states the option for paying for case management services for selected groups of patients. However, this option is not widely known nor utilized. One way to encourage states to utilize it would be to provide an enhanced federal match, for example, at the 80 percent level.

The availability of support services to maintain AIDS patients in the community is also essential, as we demonstrated in New Mexico. Many of these services can be offered to AIDS patients under the Section 2176 waiver but a number of states have expressed reluctance to use this mechanism because of the difficulty in obtaining the waiver. States might benefit from having the option to provide these targeted services without a waiver. In addition, some of all of these services could qualify for enhanced match.

It is impossible to talk about improving access to needed care without discussing reimbursement. As the experience of my hospital illustrates, we cannot continue indefinitely to absorb huge losses on medically necessary care provided to individuals with AIDS or other catastrophic illnesses. We need to identify new methods of reimbursing providers for heavy care patients, perhaps through demonstration projects. It is also imperative that alternatives to hospital care are adequately reimbursed so that there is an incentive to provide care in the most appropriate setting.

While many of the initiatives discussed here can go a long way toward addressing the gaps in our current health care system, we must recognize that one of the characteristics of the AIDS epidemic that has distinguished it from other catastrophic illness is its concentration in certain geographic areas. Even if we are able to implement sorely needed changes in our financing system, some areas may still continue to bear a heavy burden, such as New York, California, Texas. To deal with this strain, a block grant assistance program based on prevalence might be explored. However, it is imperative that efforts to deal with the financing of AIDS care not be limited to a "quick fix" approach, since regretfully it appears that we will be dealing with this disease for many years.

Over the past several months your Commission has conducted a very thoughtful exploration of the multiple challenges that AIDS has put before us. However, I would venture to say that few issues are as profound, and as difficult and as complex as the needs to address the financing of care for individuals with HIV. Ultimately, our ability to provide the many services needed by these individuals depends on the viability of our insurance and payment system. THe efficacy of the recommendations you make will depend heavily on your ability to identify mechanisms by which sorely needed action can be funded.

On behalf of my hospital and the American Hospital Association, I thank you for this opportunity to share these views.

CHAIRMAN WATKINS: Thank you. Dr. Parrott?

DR. PARROTT: Mr. Chairman and members of the Commission, I'm Doctor Robert Parrott. I'm Director Emeritus of Children's Hospital and a Professor of Child Health at George Washington, both here in Washington.

Today I'm speaking to you on behalf of NACHRI, which is the National Association of Children's Hospitals and Related Institutions. You have our extended written testimony, and I'll summarize by describing briefly why financing issues are so critical to the future inpatient care of children with HIV infection, and will also give you some specific recommendations for short-term and long-term actions.

There are four basic points. First, children's hospitals are major providers of care to children with HIV infection. NACHRI has found that 19 of our member hospitals alone care for more children with HIV infection than the number of pediatric AIDS cases reported to CDC for the whole nation. That's using the official definitions. Two hospitals alone account for nearly 300 cases. This is consistent with the fact that children's hospitals are often urban hospitals, specializing in care for both very sick and very poor patients.

The second point is that the rate of growth in the number of pediatric cases and adolescent cases that our hospitals are following is alarming. Since 1983, the number of new cases seen by children's hospitals has doubled. NACHRI projects that by 1991, on the average, one out of every ten pediatric hospital beds in the country could be occupied by a child with HIV infection. Our own hospital projects that by 1991, we will have seen a total of more than 800 cases of HIV infection, almost 500 of which will be still living and undergoing care in that year.

The third point is that everything we know about the care of children with HIV infection tells us it is more expensive than caring for either adults with AIDS or other children in our hospitals, including my own hospital. The average charges for the care of children with HIV infection are roughly twice those for other children. This reflects the fact that these children are sicker and require significantly longer stays, often including intensive care in the hospital.

Just to give you some examples from our hospital in fiscal year 1987, in a survey of 45 HIV-infected children who were predicted probably to need to be in the hospital and a look back at what happened, the length of stay for the HIV infected was 13.9 days and about half that for all patients, including those with HIV infection. The charges per day were $1,460.00 for HIV infected and $1,261.00 for all, adding then to total charges of $20,000.00 approximately for the HIV infected, something over $9,000.00 for all patients.

It's particularly important to recognize that in children's hospitals these data have not yet been inflated by unnecessary hospitalizations, since until recently we've essentially been successful in placing children who are cleared to be discharged.

The final point is that the financing of care for these children falls (as everyone has said, it's also true of pediatrics) largely and increasingly to Medicaid. Again, in this same study from our own hospital, we examined the payor mix among agencies responsible for payment for HIV-infected children, as contrasted with all admissions. The three Medicaid agencies in this area were responsible for 73 percent of HIV patients as compared with 29 percent for all patients. Three times more responsibility than for all patients. Private payers, HMOs, Blue Cross/Blue Shield covered 8.5 percent of HIV infected patients versus 68 percent of the total patients in the hospital. The number of children in so-called "self-pay" status was 18 percent for HIV infected, and 11 percent for all.

Children's hospitals are acutely aware of the limitations of Medicaid, as have been referred to by others already. Medicaid is severely inadequate in its payment for children's hospital care for all pediatric patients, whether or not they have HIV infection.

On the average, more than a third of the care that children's hospitals give is for poor children, more than a quarter of the children under Medicaid. Nationwide, Medicaid, on average, reimburses children's hospitals for only 62 percent of their charges and 77 percent of their costs. In some states, it's much, much less, depending upon the liberality, if that's the way you want to put it, of the Medicaid system in the state, the amount of matching that the state provides.

These four points lead us to urge the Commission to recommend a combination of short-term and long-term actions. For the short term, we urge your support for three legislative proposals now pending in Congress that could provide relief to those comparatively few hospitals that are already bearing the burden of inpatient care for children with HIV infection.

The first is the Pediatric AIDS Resources Center Act, S.1871 and H.R.3648. This would authorize $25 million annually over three years in grants to hospitals already experienced in the care of children with AIDS. The grants would support their efforts to establish model centers of care. It would not be a method of payment per case, but would enhance what the individual institutions could do.

The second proposal is the Abandoned Infants Assistance Act, S.945 or H.R. 3009. This would authorize $20 million annually, again, over three years, in grants for foster care demonstrations to alleviate the problems of children abandoned or potentially to be abandoned in hospitals, particularly, those with HIV infection.

And, the third proposal is to support Section 302 of the Medicaid Infant Mortality Amendments of 1988. This would require, for the first time, that all state Medicaid programs make payment adjustments for extremely high costs and long-stay cases of infants who are receiving care in hospitals that already have disproportionately large numbers of Medicaid patients. This is particularly important in the face of the growing number of infants born with AIDS, when you consider that about half of the states now place absolute limits of some kind on their Medicaid patient payments.

This last proposal leads to our recommendation for long-term action. That is, the Commission should advocate comprehensive reform of Medicaid, the nation's largest program of public funding for the health care of children. The incidence of HIV infection, increasingly, among low-income families, only magnifies the already serious shortfalls in Medicaid coverage for poor children, and the burdens borne by their care providers.

Among children's hospitals, Medicaid accounts for about one half of all our uncompensated care. We urge comprehensive reform of Medicaid, because Medicaid reforms, designed only to respond to the crisis in HIV infection, will aggravate the limited coverage Medicaid provides for other poor children. Comprehensive reform must include expanded eligibility, expanded coverage, particularly for home care services, and increased funding. Otherwise, states will continue as they have in the past simply to redistribute their limited pools of Medicaid funds in response to new Medicaid requirements.

In conclusion, we commend the Commission for its attention to the special problems of caring for children with HIV infection, both in your interim reports and in your hearings to date. And, I'll be glad to try to answer any questions you may have.

CHAIRMAN WATKINS: Thank you, Dr. Parrott. Mr. Yezzo.

MR. YEZZO: Admiral Watkins, Commission members, distinguished colleagues, the first time that I spoke to you, about four or five months ago, there were 900 people with AIDS in hospital beds in Manhattan in New York City. This morning, there were 1,504. By 1991, there will be 145,000 PWAs in the United States, with a cost that some experts estimate to be anywhere between $8 to $16 billion. Medical care costs now for PWAs is $1.1 billion, and will rise to $8.5 billion in 1991. The figures do not include AIDS-Related Complex (ARC) or HIV-related disease. I'm sure the Commission members have heard this before -- but the distinction between ARC and full-blown AIDS is becoming a finer and finer line. All people that are HIV positive must be considered the same.

We have to develop comprehensive care plans. We, the hospitals, must develop comprehensive approaches to caring for people with HIV disease. We all recognize, and my colleagues and I all agree, that people must be moved out of the acute-care setting as quickly as possible when they no longer need an acute level of care, and to put appropriate resources into appropriate levels of care for this very complicated illness and all the other related illnesses that are associated to this virus.

A hospital providing comprehensive AIDS care must have an acute unit, and obviously, must have the high-tech intensive medical and surgical care capabilities for intervention of this disease. But a hospital must also have the ability of moving the patient to lower levels of care, into an environment where that patient can get the appropriate level of medical/surgical nursing that he or she may need, the appropriate level of psychosocial intervention, the appropriate level of all of the ancillary disciplines that are necessary. Not too much of one and not too little of another, but what is deemed appropriate.

All too often, the history of the reimbursement methodology in the United States has been driven for understandable reasons by available dollars. However, when it applies to this disease, we have learned something with our past experiences with other diseases: we must programmatically describe what we as health care providers are going to provide for people with AIDS.

We must then, in coordination with government, city, state and federal, come up with a logical game plan, something that is a little bit of a give and take. Thank God, in New York State, we have a very good relationship, if I may say, with the State of New York, Office of Health Systems Management, and I'm glad to see that there is going to be a person, in Ray Sweeney, who will be testifying later on.

In the experience of St. Clare's Hospital the ability to put together an acceptable reimbursement rate, has been crucial to the success of the program. It is also significant that the State of New York has recognized the need to establish intermediate care facilities. The state did not get hung up on what I call archaic and outdated nomenclature, such as skilled nursing facilities, which congers up a Medicaid reimbursement rate that is totally inadequate to care for people with HIV disease.

So, I think what we are forced to do, and I say "we," because no longer is the onus on the hospitals, or on you as Commissioners or on the government, but we collectively must come up with a new nomenclature. We must recognize the need to move patients with HIV disease into appropriate levels of care to get them as quickly as possible into as healthy a state as possible, and provide competent and comprehensive outpatient services. As the PWAs before had mentioned, the system must be able to recognize the fact that many PWAs can go back to work, they can pay their share back into the system, if they are diagnosed early enough, treated competently enough, and are pleased in an environment that focuses on their needs. This is not the way the system is currently structured.

Don't make PWAs fit into our system. Let's make sure that we can appropriately address their particular needs. When you are talking about financial resources, we must apply the appropriate financial resources to their particular needs. This involves having PWAs able to move in and out of facilities structured to meet their needs at any particular stage of their illness. Look at our length of stay in our acute-care facilities for persons with AIDS.

By having these other sub-systems set up, to be able to provide sub-acute levels of care, care in the home, better support in the home, better social service and case management systems, to keep people with AIDS out of that high-cost area, we can lower the length of stays in hospitals for PWAs.

Being located in New York State, it is easy for me to say a lot of these things. In terms of reimbursement, St. Clare's Hospital, for example, had an average per diem payment of about $420.00 a day pre-DRGs. Post-DRG, however, we are paid for our general medical and surgical patients on the discharge diagnosis.
For patients with AIDS, since we have established a comprehensive treatment center for the care and treatment of people with HIV disease, we get $568.00 for an acute stay.

We are now negotiating the addition of a sub-acute facility at St. Clare's, which will be on a separate unit, and we are looking at reimbursement rates in the area of $380.00 a day.

And then below that, we are now in intense negotiation with Dr. Boufford's people in the Health and Hospitals Corporation, working in collaboration to put together a housing situation for PWAs that will be a kind of intermediate care facility, with certain medical and social service intervention. The facility would also allow the PWA some independence so that they can move in and out of that facility during the day to the extent that they are physically able to do so.

The best answer is for people to return to their own home, but because of the disease and the stigma involved, many people are abandoned and thrown out of their home.

I echo the thoughts of my colleagues again, especially those of the American Hospital Association, where in certain parts of the country the difference between the Medicaid reimbursement and the amount of money that the hospital is spending on an AIDS patient could be upwards of $250.00 a patient day. This is not going to force the cooperation amongst my colleagues, and I wouldn't blame them. The system is not one where people are encouraged to care for people with AIDS.

But, the onus is not only on the Commission, nor should it be only on federal or state governments. The onus should be on us together, that we as providers must come up with as comprehensive a care package as possible, which would enable patients to move through our health care system as quickly as possible, to be able to apply available resources to the appropriate level of care. And, if we can do all of those things, then I think we will be at least economically managing an almost unmanageable problem.

We all recognize that the dollars are going to be spent, albeit, from what we say here today. It's going to be necessary. We all look at it, thank God, that in this country, health care is an inalienable right of any person. But, I think if health care providers can manage care more economically, and move people through the system quickly, then I think we'll be able to stretch that dollar further.

There is detail to my testimony, and I will not do the same thing I did to you the last time by putting everyone to sleep, but I have some recommendations that I'd like the Commission to listen to.

Third-party payers, and in particular, the Medicaid program, must begin reviewing and revising the services eligible for reimbursement, as well as increase the reimbursement rates for those services. Again, we need to keep in mind that the onus should be on the provider to fit into that enhanced reimbursement system and to provide more appropriate levels of care appropriate to the manifestation of the disease.

Reimbursement rates must be programmatically driven. The focus should be on the development of appropriate services for individuals with HIV-related disease, followed by the development of licensure categories and reimbursement rates. Throw away names such as skilled nursing facility, health related facility and intermediate care facility for people with HIV disease. Let's come up with different names, with different types of rates, with different types of regulations, which are specific to this illness and which can facilitate the movement of that patient through the system quicker.

States should be encouraged to provide Medicaid coverage for optional services, especially home care. Hospitals and other health care providers must have increased access to capital, to develop sub-acute facilities and innovative programs to meet the needs of individuals with HIV-related disease.

We are fortunate in New York State to be recognized by the Commissioner of Health, and also by an awful lot of philanthropic organizations, as a model program. But what St. Clare's Hospital is doing is showing other facilities in all parts of New York City and especially, in other parts of the country, that providing care to PWAs can be done. If we can do it, then anyone can do it. And, other providers in other states, and other governments, at the state and local levels must recognize the ease with which this can be done.

The private sector, including health supporting foundations, have to demonstrate a greater commitment to meeting the needs of individuals with HIV-related disease. For example, private health supporting foundations must allocate additional funds for AIDS-related projects.

And lastly -- and I thought through this one on the plane coming down because of a recent discussion in doing my hospital budget with my pharmacist -- I think it must be one of the recommendations of the Commission to caution the federal government, because they are the only ones who can intervene, to look at not only the high cost of AZT, which I know this Commission looked at very thoroughly and very carefully, but all the related antibiotics that and seem to be of some benefit when used in combination with many of the experimental drugs for this disease. We are noticing a four-fold increase in cost for all antibiotics that we have found effective when used in combination with AZT.

And, as that last throw in, I just caution the Commission that we do not overspend unnecessarily on drugs that can be purchased much cheaper if the federal government had an impact on the way pricing is done by the drug companies. Thank you very much.

CHAIRMAN WATKINS: Thank you, Mr. Yezzo. Let me open the questioning, and then I'll shift over to Dr. Conway-Welch.

Dr. Parrott, I've heard reports that children's hospitals have actually shouldered what should be local government's role in providing social services to the families of HIV-infected children. Is that the case, and, if so, how long can you really sustain that kind of "go it yourself" approach?

DR. PARROTT: I think I can introduce the answer to that by stating that many large cities have not had fully adequate social services for poor people, and since many infants or children fall into that category, or their parents do, this is another example of how HIV infection compounds an already inadequate system.

I think anecdotally that what you were told, or you had heard, is correct. I do not know enough about each of the major cities at this point to be able to say. I can say that the city government in Washington is doing its best, and, in fact, we have been working very closely, our hospital, Howard University, D.C. General Hospital and the city government, which has a special Pediatric Working Group, to try to pull the whole system together. That system has to start with diagnosis, treatment medical, but when you look at the whole system for infants and children, the medical is really a small part of it, and, in fact, the lesson, perhaps, for this panel is that the more that can be done pre-hospital, after hospital, foster care, social services, hospice type for children, the more that can be done along those lines the less there will be the threat of babies being left in hospitals, or needing to stay in hospitals.

I mean, as some of you know, in the last number of years there has been a lot of advance in home therapy, and that's true also for infants and children. It's a little more complicated, and you need people who are adept at it, but you can do home therapy for children as well. And, we think that would cost less, and is more likely to give the infant child and family a life that's closer to normal, which should be our goal until or unless there is a cure.

CHAIRMAN WATKINS: We've been informed by a number of witnesses, that in certain cities, such as New York City, in the public hospitals, that the projected case load of infants who have contracted the virus perinatally could well bring some of those hospitals to their knees.

The families don't have the money in general, the work is going to go on, the intensive care, the human resource costs are incredible. Do you share that view?

DR. PARROTT: Yes, indeed. In fact, for Washington, as we project the number of cases, which is three, four years behind New York/New Jersey, but once the virus is into the drug abusing community, and some heterosexual spread occurs, infants are going to be born who are infected. And so, we have projected, as I mentioned, a doubling of cases for each of the next few years from infants, and we're also saying, double the number of new cases in adolescents.

CHAIRMAN WATKINS: The social work aspect, the social side of that equation, seems to me to be every bit as complicated and one that we don't want to forget in our addressal of the integrated approach that Mr. Yezzo was talking about. We have to consider all aspects of that particular part of this epidemic in a unique way, perhaps.

We have tried to focus on that a little bit, because of some of the frightening statistics, that 1 out of 61 babies born in New York, will have HIV for example. The numbers projected for 1991 are rather disturbing from the ability of the hospital system, or the related health care delivery system, to handle anything like that coming on us that rapidly, for a variety of reasons, not just dollar resources, but the human resources needed to handle it.

DR. PARROTT: I agree, and I do think it is the out-of-hospital aspects that need as much or more attention than the in-hospital aspects.

CHAIRMAN WATKINS: Let me ask you just one more question. Is the care for children under age 21 reimbursed for home care by Medicaid now? I understand it's not.

DR. PARROTT: It is not.

CHAIRMAN WATKINS: Should it be?

DR. PARROTT: I believe it should, yes.

CHAIRMAN WATKINS: Any of you others have any feelings about that?

DR. BURNSIDE: Admiral, we'd be delighted in Texas if they were reimbursed for hospital care. I'm serious about that. It's a plea for a level playing field, in that the discrepancies state to state are just unconscionable.

You might ask, why should someone from New York or California, that has a very good Medicaid program, why in the world would they support an increased Medicaid standards in the south? Well, it would be to their very best interest. For one thing, I think Greyhound must be making a fortune on one-way bus trips from the south to New York City and San Francisco. There is clearly a migration, as you heard this morning, of the terrible frustration felt by these patients, and the extraordinary lengths they will go to seek the proper medical attention.

CHAIRMAN WATKINS: Do you have any data on that, Dr. Burnside?

DR. BURNSIDE: No, sir, I don't.

CHAIRMAN WATKINS: Because this has come up before.

DR. BURNSIDE: It is anecdotal.

CHAIRMAN WATKINS: The migratory aspects of the HIV epidemic, we've heard it from San Francisco very loud and clear, whether it is anecdotal or supported by facts, we don't know.

DR. BURNSIDE: We see it in a small --

CHAIRMAN WATKINS: Good programs are a drawing card, a magnet --

DR. BURNSIDE: That's right.

CHAIRMAN WATKINS: -- where you can obtain these services more sensitively from the human side, people are migrating that way. Is this an intent on the part of the State of Texas, to force migration out?

DR. BURNSIDE: No, I think not. I think that's a little ungenerous, but we see it within the state, we'll see it that some of the poorer counties, who have no public health facilities, folks from those areas who are HIV positive, or AIDS, or ARC, will find their way into Dallas County, or they'll find their way into the Houston area or the San Antonio area to get care. And, it's the taxpayers of that county who are providing that care, not the taxpayers of the state, nor of the nation.

CHAIRMAN WATKINS: Mr. Yezzo?

MR. YEZZO: In recognition that the Medicaid dollar is 50 percent federal, I can speak only for St. Clare's Hospital, but what is going on in Texas, from a societal point of view, as well as from a health care provider's point of view, is almost unforgivable. My colleagues in the south get our full support in addressing the inadequate funding that they are receiving now.

Eventually, providers are going to be forced to put people with AIDS, or people with uncovered illnesses, out, refuse to provide care, which is almost unheard of, or close their doors. That's basically what we are faced with.

CHAIRMAN WATKINS: Dr. Conway-Welch?

DR. CONWAY-WELCH: Two questions, Mr. Chairman, to Dr. Boufford and Dr. Parrott.

I heard you particularly talk again about expanding the CDC definition, and I wondered if you could once again go over that again. It seems to be something that continues to create confusion and problems for us.

And, Mr. Johnson, you spoke more about reinsurance programs specific for AIDS, and, perhaps, you could expand a bit on that. If we could, perhaps, start with Dr. Boufford?

DR. BOUFFORD: Yes. I think, specifically, our concern and that of Mr. Yezzo is that use of CDC-defined AIDS for purposes of epidemiology does not encompass the same type of care needed by people who are HIV infected. As I mentioned, we have on the average 450 CDC-defined AIDS or ARC inpatients a day, and we believe there are probably 30 or 40 percent again as many people in the hospital with HIV-related infection who are not eligible for social services, who are not eligible for the enhanced reimbursement rates, which are coming through, at least in New York State, under the DRG system, and, yet who are requiring the same intensity of care as many of the AIDS patients. It's just a question of the stage of their illness.

And, the, denial, if you will, of recognition of them for social services and medical insurance purposes is a disadvantage both to providers and to the individuals when they seek care following hospitalization.

DR. CONWAY-WELCH: My understanding was that CDC's expanded definition was a step in that direction. Am I hearing that it's not enough, or it is too --

DR. BOUFFORD: I think it was very important, but as some of the ambulatory therapies and prophylactic therapies evolve further. There are probably going to be more people sustaining an HIV positivity with intervening infections without progressing to full AIDS or ARC diagnosis. These persons are going to need to be eligible for these kinds of services. And, though I think it was an enormous step last July when the definition was expanded, as the disease evolves so does our understanding of what's necessary and a further expansion appears to be a reasonable next step for purposes of coverage.

DR. CONWAY-WELCH: When we hear the problems that are currently being encountered by people who do meet the definition, it seems like there is another infrastructure of people who don't who are poised until they get sick enough to move into that category, and we aren't even addressing that properly. We're leaving that up to you all to deal with. We aren't addressing that in terms of the reimbursement issues at all at this point.

DR. BOUFFORD: That's right.

DR. CONWAY-WELCH: And, they've kind of hovering, waiting.

DR. BOUFFORD: That's correct.

MR. YEZZO: One comment, and please correct me, Doctor Lee, if I'm wrong. Scientists in 1982 said that roughly 30 percent of people who were HIV positive, would eventually get sick and die.

At that time we didn't have enough epidemiological data to measure morbidity and mortality. The numbers now are looking more like 65 to 70 percent of all those people that are HIV positive are eventually going to get sick and die. Many people are now saying that number is more like 95 percent, possibly 99 percent.

So, we now have more information, we see more aspects of this disease and we know that everybody who is HIV positive shouldn't fall into the same category.

DR. PARROTT: You asked if I'd comment on the CDC definition as well. I think it is important to point out, which I'm sure you've heard before, that the original definition, and even the current one from CDC, is meant for surveillance to gather information and to be as sure about it as possible in reporting.

The problem is compounded with infants. I believe you've probably heard this too, but a baby born to a mother who is positive will be born with antibody. And, as of now, there is no definitive way in the first day, week, month of life to say this particular baby will be infected.

The figures have changed as to the likelihood from, I heard a report it was only 5 percent in Haiti, but up to 80 percent, but now most people are saying something around 50 percent, and my own guess is it is ranging toward 70 percent.

So, a baby born may have up to a 70 percent chance of being infected, which probably means at some point the baby is going to die, or the person is going to die.

There is a problem even during what is called the "indeterminate infection" period. That's what CDC calls the period up to 15 months of age, if no other evidence, no clinical or laboratory evidence, has been entered. Now, most babies that are in that circumstance are already in a difficult situation because, for the most part, they are born to families that are not intact and that have an intrinsic problem, primarily drug abuse. Those babies need to be followed, need to be watched.

So, in terms of funding, one needs, I think, in relation to HIV infection, to pay attention to this pre-HIV state. One doesn't like to label such babies, and tries not to, but, in fact, it is better to follow them. The consensus is beginning to move toward that, that it is better to know, and to follow, and to inform foster parents, et cetera, if this baby has a potentially 70 percent chance of being HIV infected. And, it's better for the baby, it's in the baby's interest to pay attention to immunization, developmental milestones, and encouragement for good nutrition, and watching out for that first infection.

And, in fact, before long there will be treatment. We used to say, well, there's nothing you can do. But things are coming along, and there is therapy which is thought to be effective. One still formally under trial, called intravenous immune globulin, is usable and used by many for babies, because it prevents the bacterial super-infections that occur.

And, AZT is going to be studied shortly in babies, and a lot of us feel that it is important. I think CDC wants to find a definitive way of saying "this baby is infected." You can do it pretty well in an adult by identifying antibody positive, but in a baby you can't yet. There are tests that are coming along that promise value along that line, but most of us, I think, now feel the sooner you know, the better, just as with an adult, the sooner you get whatever treatment is available the greater the chance is of preventing serious morbidity and/or mortality.

DR. CONWAY-WELCH: Mr. Johnson?

MR. JOHNSON: Mr. Chairman, I am not an reimbursement expert, but I think that if you examine Medicaid as the program that people tend to look at as the support mechanism for the poor, or those individuals undergoing some life catastrophic issue, then I think that we have substantial problems relative to Medicaid.

I would refer to a document I think you probably have received in testimony once from the National Association of Public Hospitals. They have done a very intense study looking at the effect of Medicaid, and there are 17 states only that are considered to have liberal Medicaid programs and 33 considered restrictive, and that's based on a ratio of Medicaid recipients to persons living below the poverty levels. Texas, of course, is like the third from the bottom, New Mexico close thereafter, but these are states whose programs are very narrow and very limited.

If one is to examine Medicaid as a program, I think there are three areas that you could look at. Those are eligibility, coverage, and then reimbursement. I think those are the three components that you would be able to look at.

If you look at eligibility, there has been some recent movement to expand eligibility in Medicaid, particularly, women and children's programs, and that has, in fact, offered some help in increasing the women and children who have access now to Medicaid.

If you look at the State of New Mexico, however, remembering that Medicaid is a state program, state options, state coverages, and that is a discreet decision made within the state, we have a program that is tied clearly to the aid to families with dependent children program. The person with AIDS has to move through the SSI system, and although we have tried to be very responsive, that tends to get encumbered with a great deal of bureaucracies that we've heard before.

The medically needy program, in which there is a spend down aspect, although that did not sound to be positive, may have some positive characteristics. Each of those, again, crafted unique to the states that have those. 14 states, New Mexico being one, does not.

If you look at the extension of higher income thresholds as a means of adjusting eligibility, or having a national eligibility floor, so that states don't have the options and they must focus in on certain specific, for 40, 50 percent -- or, 50 to 75 percent of the federal level.

If you'll excuse my voice, I'm worried about health care as needing to cure the common cold today. I'm really struggling.

There is a review, I think, of eligibility aspects that may be done on a nationwide basis in other states.

Covered services are particularly unique features of providing the care outside of the hospital. Most programs tend to be focused, hospital oriented. You've heard many, many testimonies over the fact that there is a broad care continuum, and whether it be social work services, whether it be case management, halfway living, all types of things would require that.

Of course, focus on substance abuse, particularly, IV drug abusers, as a programmatic review in order to determine the spread of the disease through the IV drug abusers.

And, in terms of reimbursement, there are a variety of issues regarding transitional care, living payments, universal precaution in corporations. I don't want to make light of it, but the DRG factors of the payment factors that have excluded the review of universal precautions are devastating. We're going to spend about $325,000.00 in our hospital alone, again, a fairly small, rural state hospital, just on implementing universal precautions. None of these costs are reflected in anything else you've heard, that's spread through the system. The cost by social services is spread through the system. So, there are a number of things that we could do within the Medicaid program at the federal level to deal with that. We have also heard about the problems associated with antibiotics, drugs, AZT, which are dramatically influencing the costs of the outpatient care.

I think these are some of the issues that we could address as a group, and there are individuals coming who could speak very technically and very dramatically to these issues.

CHAIRMAN WATKINS: Yes, Dr. Parrott?

DR. PARROTT: I just wanted to mention, this study that was alluded to is being updated. The National Association of Public Hospitals, with the Council on Teaching Hospitals, are now conducting a follow-up in joint venture with NACHRI, so there will be more pediatric information than there was. The questionnaire is out, and the results, preliminary, are predicted to be available this summer. So, you should look for that information.

CHAIRMAN WATKINS: When this summer? Will there be any opportunity for us to take a look at some of the early drafts on that before we have to make our final report to the President?

DR. PARROTT: The man who is staffing it is in the room.

MR. JOHNSON: Dennis Andrulis from the NAPH is staffing that particular research study.

CHAIRMAN WATKINS: Perhaps, our staff can then link up, and at least get the benefit of the information to date, so that we have the very best picture going in, because I think it's a very important area for us. Yes, Mr. Yezzo.

MR. YEZZO: If I could just add one comment. In New York State, the State of New York's Office of Health Systems Management, carries a lot of weight with the other insurers, the private insurers and Blue Cross. If other state Medicaid programs are more generous, or more comprehensive, I'm sure that that would have an effect on your local Blue Cross rates as well as the other local private insurance rates. It has happened that way in New York State.

MR. JOHNSON: Mr. Chairman, if I might take just one additional moment. In a state like New Mexico, which I think represents many, many areas of the country that have AIDS in their community, but not where it is overloading all of the systems, I would speak for funds for education for those states. So that, the disease could be limited, that there could be education among adolescents, amongst various high-risk groups, so that we could modify and change behaviors to, perhaps, contain some of the impact of that disease in those areas that yet have not been overwhelmed by it. Thank you, Mr. Chairman.

CHAIRMAN WATKINS: Mr. DeVos?

MR. DeVOS: We have panels relative to education, which is another whole vast subject, which gets down to the fact that actions have consequences in our lives.

I hear one common plea here, I guess. Everybody is saying "help," and I would ask you a simple question. Are we trying to put a bunch of band-aids on the Medicare and the Medicaid program as opposed to starting new? We are starting with a new category, with children with illnesses that are persistent. We are dealing with young people, and drug abusers, poor generally, and Medicare and Medicaid were never designed for all these categories. And so, now we're trying to patch this whole thing together and tweak it a little bit, and I almost wonder if we just don't have to take a new page and say, hey, this is a new category of a disease, it attacks different kinds of people.

MR. YEZZO: If I could take a shot at that. You are pretty close to the truth. The reimbursement system -- how we got to a discharge diagnosis method of payment, and all of the crazy things in between when Social Security was first instituted -- really needs to be looked at seriously, especially as it relates to this disease. Probably, if you look at health care in the entire country, the terminology that we used in 1950 is not applicable today. In many other illnesses, and I don't think it's just HIV-related disease, but especially because the disease is so complicated, and because we know it is going to be so expensive, we really need to redefine the system.

I repeat, we can't use terms like skilled nursing facility. They don't work. They don't fit. The patients are not appropriately cared for many times in those environments, because when you say skilled -- and I can only speak for facilities in New York State -- when you say skilled nursing facility, you are really saying $96.00 a day. In New York State, when you say HRF or health-related facility, you are really saying $45.00 a day. And, when you say acute-care bed, you are saying anywhere in the area of $550.00 to $700.00 a day, depending on the facility.

Okay. We've got to get away from that. We've got to say, here's what this patient needs. Here's what we have to provide. This is what it's going to cost, and we'll give you 80 percent of the cost, or 70 percent of that, and the philanthropies will make up 15 or 20 percent, and you hospital or facility are going to show me some cost-cutting techniques, and you're going to come up and make up the other 10 or 15 percent. But, we're not even starting to do that yet, and that's what I'm personally frightened about. In New York State we supposedly have a generous system, according to the charts, and we're still having a difficult time.

MR. DeVOS: These are people who want to go back to work, who want to take care of themselves and it's a whole new breed.

MR. JOHNSON: Mr. Chairman, if I might comment, there are a variety of diseases in our country that are described in the same way. The same archaic limitations are still in place.

This group of people are just one of many groups of people that are afflicted the same way on this treadmill in health. It is a huge group of people. Not just AIDS, but other people who are caught. I guess we're distracting from the subject, but this is pandemic rather than just the AIDS patient.

DR. BOUFFORD: I would just, if I may, support that statement, especially as a public hospital provider. The visibility of the AIDS issue, the advocacy of the active AIDS groups that have brought this situation to the public eye, really have just uncovered the reality of the major flaws in our health care financing system. As a public provider, we see all categories of patients who are uninsured or for whom the insurance is focused on the acute inpatient catastrophic event and not on either the preventive side or the aftercare side, which is really the crucial question.

We see it in very sharp focus with persons with AIDS, but it's not a new phenomenon. As one of the Commissioners said earlier, it's an exciting opportunity to at least highlight the need for what I certainly believe is necessary: fundamental reform in health care financing.

MR. DeVOS: That's been the Admiral's theme from the beginning. It really attacks a much bigger problem with each clarification.

DR. BURNSIDE: I would add an agreement to that. I think that the patients with AIDS have been a paradigm of a problem and I would not urge that we single them out anymore. I think they've been singled out quite enough. To single them out with very special programs will lead the inevitable perception that you are doing that at the expense of some other groups who are going to feel terribly disenfranchised, whether it be real or just perceived. So, to address it as a much larger problem, namely the Medicaid dilemma of eligibility and benefits --

CHAIRMAN WATKINS: But Dr. Burnside, let's say you could sit down and look at Medicaid through the lens of the HIV and say, "If you're just going to solve the HIV in Medicaid, I would go this way," as the first excursion. As the second excursion you now say, "What did we do to all other health care delivery in the process? What did it cost and can the nation afford it? Oops, we went too far."

Now, we go back and we iterate again. It seems to me that you can use this incredible epidemic that we have, one of the most insidious that's ever faced the world, at least to try to come up with something that makes a more rational approach for everyone.

Now, we found many, many times that we can lean on other legislation, other protective features and sweep HIV under it. So, we are sensitive in this Commission to knowing what we're doing in all other areas. We've walked on those egg shells very delicately in our interim report. We can't solve a lot of these problems in health care delivery without nurses in the nation and we can't stamp on their forehead that this nurse is going to work on HIV specific cases and not on any other case. So, it's very difficult unless you solve the nursing shortage.

So, we've tried to find a narrow line of approach through this labyrinth of complex social and other medical issues. It seems to me that there's a way to do this without trying to say, "We want to solve only the HIV." We can begin to think in terms of HIV and watch the ramification and the spin-off.

It seems to me there's an opportunity here if we can get specific about improvements to Medicaid and not try to frighten ourselves too soon by the cost. If we want a more compassionate and sensitive society that's in better health in the future, it seems to me that there's an opportunity.

I don't know if it can be done. I don't know if the Congress would even be sensitive to it. It may be very difficult to, at this particular time, a budget deficit because of the fright of potential cost increases. But it seems to me it doesn't cost that much to take a look at new ways of doing business and finding the boundaries and the limits when you realize that the excursion into other diseases and not streamlining health care delivery may add tremendously to the financial burden.

DR. PARROTT: Admiral, I just wanted to mention that you might want to look at the Medicaid system in the state of New Jersey as having taken advantage of what one can do. It's basically a liberal program, an all payer system, but with appropriate waivers to the point that -- at least for children now...(I don't know the overall situation). The situation for children with HIV infection is as good as it can be under current Medicaid systems. Again, this depends on the state. I see you have California and Florida on the panel, but I don't see New Jersey. You may sometime want to talk with them.

CHAIRMAN WATKINS: Thank you very much, Dr. Parrott. Mrs. Gebbie?

MRS. GEBBIE: You've already explored a good number of the questions that I had. I think it will be one of the hard decisions of this panel to figure out how far we fix what's really a flawed up system and how far we fix it just for one set of patients.

We've talked a number of times about those states that have what appear to be very bad systems, worse at least than others. I don't know if any are yet labeled good. That didn't just happen. Presumably that happened because the political will in that state, the combination of citizens at large and elected officials, think that's right or think that's all they can afford or think something or other about it.

How do you read our collective will to fix this on a national scale? If we've got a third or more of the states that haven't been willing to look at taking the most generous opportunity of advantages available under the present system, can we find enough collective will, do you think, to ante up -- no matter how you do it, it's going to be more cash to fix it more broadly.

Some of you have been monitoring various federal bills and state bills. What do you think about that political side of it?

DR. PARROTT: Let me just address it briefly. I alluded to one system that a number of states are looking at which some hospitals and health care providers are a bit concerned about. It would be a way of distributing the cost of indigent care. Among all payers - the "all payer" system. In such a system, the private insurer will pick up more than they currently do or perhaps used to in the way of indigent care, Which is what Medicaid is about.

States would either work out systems that incorporate private paying insurers and businesses into involvement with indigent care or potentially there would be a mandate from a federal level that states do it. You still have to get the money, so the money's got to come from someplace. But one approach might be to encourage more all payer systems.

MR. JOHNSON: If one examines the array of states that are considered to be more liberal, you'll find they are states who began with greater wealth, greater industry, both coasts and as you move forward down into the more southern states over to the more western states, then you see the programs failing.

Each state makes it own political and economic decisions on how it will fund its Medicaid program. We attacked this within our state. Each January, as our legislative session begins, we vigorously try to increase eligibility coverage. It's a very slow process. It's a political philosophy that's embraced in the state of New Mexico. It's very conservative politically and has very deep roots in what they believe they should be doing. It is very difficult to change that.

Most recently in our legislative session, I personally sat on a legislative committee on AIDS that had 16 legislators and myself. We met for six months and the net result was some very marginal good and we didn't do anything bad. I guess you would consider that to be extraordinarily successful.

DR. BOUFFORD: I think there are a couple of problems at a more philosophical level which is, I think, a little bit of what you were asking. It seems to me from sitting in a municipality like New York City, in a state like New York that have had a historical commitment to public service, both social services and medical services, that there are two basic problems we face as a public provider which I think could be extrapolated more broadly.

One, in the era of cost containment is cost. If you're adding cost to the system, you either add funding or you reallocate internally, meaning that you take funding from someplace else. This decison becomes automatically a political one.

I think it's quite clear if you look at the Medicaid system or other systems that there are ways of redistributing what are very significant amounts of dollars in this health care system. For example, in New York City, the state pays $60.00 a visit for outpatient services at a hospital and $11.00 a visit for a private physician providing the same services under Medicaid. That redistribution could take place. For a private physician in practice, a specialist gets $35.00 or $40.00 for a certain visit under Medicaid, while a family practitioner providing the same service gets $11.00. So there are dollars in the system that could be redistributed. That is a political issue and requires political will to change.

The second thing, it seems to me, is I think the citizenry. Even in a city or a state like New York, which has had this historical tradition of public service, it's very hard for people to see health services as a public service like they see police protection, fire services and education. I think we have a situation where the people who depend on the public services for their health care really are not a very strong constituency and are not joined by people who have access to care through their employers and other private mechanisms.

So, it seems to me that in those kinds of instances a sort of coalescence at the federal level around people in this society who do not have access really has to raise that consciousness. When faced in a city like New York with a $500 million deficit, health services versus police protection versus fire versus public education are very difficult choices to make. Then the issue is who is the constituency for each of those services? That's how the decisions get made.

MR. YEZZO: Mrs. Gebbie, I think that the federal government can come up with a guideline. All of your recommendations and all that was said at all these meetings can be coalesced into one book which becomes a federal policy on caring for people with HIV disease. But then there's a question of responsibility. The federal government will mandate that this minimum standard be met, regardless of what the locality says or has said that it is going to do. But they obviously have the authority to mandate a minimum standard. Right now we have no standards.

I think that my colleagues from the South and the Midwest are in need of support from this Commission and the federal government.

MRS. GEBBIE: If you had to pick one thing to mandate out of that great array of things you've all mentioned -- and I discovered at least two of us are thinking the same way because somebody listed three critical pieces and I had already written them down -- either making what are currently optional programs mandatory, such as the medically needy or the pre and post hospital care, or mandating coverage up to higher income levels or mandating that you paid more fully for the covered services. Can you put those in any kind of priority order or are they so intertwined that you can't separate them?

MR. YEZZO: Can I take a shot at that? The point that I've really been trying to make and it takes me more words than necessary to make points half the time -- in a comprehensive AIDS center you need to have all of those pieces that I mentioned. You need to have outpatient services, you need to have home care available, you need to have dental services, you need to have services for the IV drug abuser who is HIV positive, you need to have acute services and you need to have sub-acute services so that the system works. If you are stressing one piece in that system, then you're going to have patients backing up on you. You're not going to be able to move them through the system.

In that same way, you need the whole package. I think it's too tightly wound. If you took one thing, it's going to have a push and pull effect on the rest of it.

MRS. GEBBIE: You simply can't separate them? You'd want to do them as a package.

DR. BURNSIDE: I think that you could at a federal level establish the minimum eligibility point on the federal poverty scale. Admittedly, that is not going to do much to assuage the inequities that occur from state to state in terms of what those benefits are going to be. But at least it defines who it is that's eligible on some kind of a national standard. It leaves the state still with the directive or at least their own prerogative to decide what it is that's going to be included in those benefits.

MRS. GEBBIE: But you'd do that first?

DR. BURNSIDE: I would do that first. I think that would immediately enable a number of currently disenfranchised to avail themselves of whatever services are currently available. That in itself will cost states and the federal government a lot of money, but at least it declares that we won't as a society tolerate the absence of health care below certain levels of poverty.

MRS. GEBBIE: What is the risk that one of your two states, if told you have to cover people up to 100 percent of the poverty level would then slash the services available to all of those currently covered in order to spread it --

DR. BURNSIDE: Texas would probably become a nation again. It's political obviously. You're going to have a great deal of difficulty if at the federal level you take what has been traditionally a state run program and say, "Okay, here are the rules now." I think you can urge it in that direction.

MR. JOHNSON: In New Mexico, we still are suffering from the crisis of oil and the state would not have the money to do it without substantially raising taxes. It would create an impact, very dynamic impact within the state of New Mexico.

DR. BURNSIDE: Similarly in Texas. In Dallas County, there current guesstimate is $10 billion worth of property which is in bankruptcy.

MRS. GEBBIE: Does that argue in your minds then that not only should we do all of those other three things that Mr.

Yezzo says have to be done together, but that the federal portion of the whole thing should be increased from the present split to some higher rate?

MR. JOHNSON: As I listened to the Chairman, I think he provided some sage advice. All of the attributes of the AIDS epidemic are representative of the problem of total health care. Perhaps if one could develop a model that embraced the HIV infection and looked at all of the components that are deficient and defective in our system, you might be able to develop a model that could be more broadly expanded at the appropriate political time. I don't think that there's anything in AIDS that's absent from the crisis in health care.

MRS. GEBBIE: I understand that option that the Chairman presented and I think that's a very legitimate one. My question though is either in that option or in the perfect fix, because of the problems that Texas and New Mexico and other states have had, will it be necessary to also look very seriously at upping the federal proportion in order to avoid states leaving the Union or whatever they would do.

DR. BURNSIDE: It is a matching program. The more the state is willing to commit, the more the federal government will come in with. So, it is a shared program and if you increased the roles of those who were eligible, it would not only mandate the state to ante up a bit more, but it would also call on a greater participation from the federal government.

MRS. GEBBIE: But at the same proportion on an enhanced proportion?

MR. JOHNSON: An enhanced proportion in specific areas might encourage states to adopt services that they don't know.

DR. BURNSIDE: Yes, that's true.

MR. JOHNSON: Instead of at 50 cents, make it 80 cents or some enhancement.

DR. BOUFFORD: I think also if some of that targeting was to the sort of non-hospital services which have been very often left out of plans or of requirements, that would be important. Not just for AIDS, but generically and certainly for AIDS.

And also, the issue of more creative uses perhaps of federal support in terms of things like paying the difference that would allow an individual to stay longer on employer provided insurance if they are disabled, allowing the federal subsidy for copaying, to keep them on that benefit so they don't drop into Medicaid or into uninsured as quickly and then have to spend down into Medicaid, thinking of the federal role at the interface of various existing insurance systems at least to keep people in their system of origin or to upgrade them more into the private sector. That would probably be more cost effective rather than what we tend to do which is allow people to just drop from one catastrophic benefit into another. This ends up being the most expensive model on the public toll, as it were.

MRS. GEBBIE: Thank you.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: Most of the questions I had written down have been dealt with extensively.

I'd like to follow up one thing though. I have some difficulty putting myself in this position, but let's say that I'm a youngish fellow who has very little in the way of income and I'm becoming ill now. The first thing I've got to do is show up at an emergency room. I have no other way of presenting myself to the medical profession. Now, of course, having little previous contact with the medical profession, I'm probably very ill now so I'm going to require a hospital stay for a period of time. But that's not necessarily going to last forever. As Dr. Boufford pointed out, I'm going to rapidly change between the levels of care that I need.

How is this managed? It's basically emergency rooms that are handling all of these decisions. I'd like just a little bit more definition as to -- perhaps, Dr. Boufford, you could help me out with understanding how a person faces this.

DR. BOUFFORD: Well, I can speak about our system, when it works, which I hope it does most of the time at this point. We have essentially had an interdisciplinary team approach to case managed patient care for persons with AIDS for several years. What would happen after your initial visit in the emergency room is presumably you would, if you were ill enough, either be admitted or be evaluated and referred to an AIDS clinic or to the primary care internal medical clinic for a follow-up visit. If you ended up in the hospital, you would have a case manager, physician team or a nurse practitioner team and a social worker --

DR. LILLY: And what's my relationship to that person then after I get out of the hospital?

DR. BOUFFORD: They would be your ongoing providers. You would be referred back into a hospital based clinic and managed out of that clinic. Or increasingly what we're trying to do is move into community based settings. For example, with Bellevue Hospital, we have not only the hospital based clinic, but also the Community Health Project in Manhattan, which is a smaller center providing more intense personal care, more intense follow-up with referral back to the back-up hospital as you got sicker or if you had to be readmitted.

DR. LILLY: Now, was this system invented for AIDS or did you adapt this from something that you were using for other types of illnesses?

DR. BOUFFORD: No, this is the essence of essentially a primary care model of care that we have been trying to implement in our system for the last four or five years in at least the major specialties of internal medicine, pediatrics and OB/GYN. But we have focused it especially on the AIDS cases because it seems to be a much more cost effective and humane way of managing a complex association of care and the levels of care.

DR. LILLY: It's only existed for four or five years and AIDS has been around for a good bit more than that. So I would gather that AIDS has been the impetus for putting something like that together.

DR. BOUFFORD: The primary care notion has been around for a very long time. I'm speaking really about reorganizing public hospitals' delivery of outpatient services, which is what we've been focusing on more recently. But clearly, the essence of the private physician model is exactly this model. When you try to extrapolate it to institutions, it requires a little more juggling.

DR. LILLY: That's what I was basically trying to get at. To what extent does the patient who must rely on the public hospitals and so forth have anything comparable to a case manager or a private physician?

DR. BOUFFORD: I believe they do. Our system is designed to provide that and we have been getting enhanced resources to focus on a team approach to care. And now that we have all the levels of care available, long-term and acute, I think we do a reasonably good job with that, especially with the social worker following up after discharge to make sure the patient doesn't get lost in the system.

I think the thing that concerns us as public providers is the early access question before a person becomes acutely ill and then our ability to manage the long or complex ambulatory based care of a patient on various prophylactic or other medications because the level of organization required in our high volume ambulatory care systems is much more difficult than that in a private physician model or a small community health center model. That's what we're looking forward to trying to prepare for.

DR. PARROTT: I just wanted to say that pediatrics is, in a way, a leader in primary care. But there have also been models within pediatrics for this type of case management system, as in the management of infants with birth defects of various kinds or the disease called cystic fibrosis, both of which have long-term consequences and involve the whole family.

Now one person, the case manager in the kind of system Dr. Boufford's talking, about is not necessarily a physician. It's usually some professional health worker. But it can throughout a community be extended to involving volunteers. That's what a lot of people are talking about in terms of HIV case management.

I just want to take one more minute and turn you into a young woman with the same circumstances that you posed who has now been pregnant and has had a baby. She's been a drug abuser. She and the baby have been identified as HIV positive. The baby has now entered into a case management system and, whether sick or not, is being followed.

I think one thing that needs to be given attention is the probable lack of concentrated attention to the needs of women in those circumstances. As you've heard earlier, there are organized groups among gay and lesbian persons. The woman usually is involved in drug abuse, a problem that we have not addressed well in this country or anyplace in the world probably. That's the problem of drug abuse. We are not keeping up, we are not educating properly, we are not keeping drugs out of the country, whatever. At least it's our observation so far that the mother is lost and we may be taking care of her baby and she may or may not pay attention to our advising her to go to wherever we identify to get her into a system. So, I think at some point, if you haven't had a panel on women, you should give attention to their needs as well as those of their children.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: First, a few specifics. Mr. Yezzo, did you say a four-fold increase in those antibiotic costs over the last, what, year or so?

MR. YEZZO: That's correct. Specifically amphotericin comes to mind and I am only reacting to the recent meeting I had with my pharmacy director. Just about all the antibiotics that are used in combination with other types of drugs in caring for persons with AIDS have gone up in price four-fold.

DR. LEE: That is incredible. You're talking bactrim too?

MR. YEZZO: Yes. Dr. Lee, not to make light of a very bad situation, but you know we have 200 people in my clinic alone on AZT. When the bactrim and amphotericin salesman brings cakes to the physicians made out of the shape of their pills, I get very concerned. That's not meant to be funny.

DR. PARROTT: Did you mean to say that the number of drugs has increased and therefore the total cost -- the cost per pill?

MR. YEZZO: That's correct. The cost per individual agent has gone up.

DR. BOUFFORD: I'd just like to add one thing. The cost of rubber gloves has doubled in the last year, interestingly.

DR. LEE: This was brought up by the people at San Francisco General. We've already taken a lot of note of that in our Commission reports already. We're going to, I hope, look at it further.

CHAIRMAN WATKINS: Do any of you have the answer to the question? We were given a figure of $80.00 a case now as opposed to $30.00 a case a couple of years ago at San Francisco General. I don't know if that figure is valid.

DR. BURNSIDE: A case of latex gloves?

CHAIRMAN WATKINS: Yes.

MR. YEZZO: It's $86.00 a case in New York.

CHAIRMAN WATKINS: The question is, is there indication from your point of view that a kind of pirate operation is underway or is there a legitimate reason for the price increase, that is the quality was so enhanced in the interim period that we expect some kind of increase in cost? I just don't know, but we're hearing it enough and it raises the question of profiteering on this disease that is always an anathema to those of us on the Commission. But you brought it up now. What do we know about it? Mr. Yezzo at St. Clare's Hospital, what do you say?

MR. YEZZO: From our experience, there is a definite shot at profiteering. I just have a generally suspecting mind and it just seems a coincidence that just about every item that we are now using in the care and treatment for people with HIV disease has gone up. Some of the price increases have been gradual, while some have not been so gradual, but everything has gone up. This is especially true in my emergency room, as probably in every emergency room in the city. We're treating everyone as if they're HIV positive. There's no distinction between patients that come in. If we see an old grandmother that comes in, she will be looked at the same way that that single 28 year old male or that 15 year old IV drug abuser.

CHAIRMAN WATKINS: I'm talking unit cost now, not the degree to which you have to expand the total inventory. I'm interested in unit cost.

Dr. Boufford, do you and Mr. Yezzo have specific data on the costs and cost growth on these kinds of universal protective equipment?

MR. JOHNSON: Mr. Chairman, in 1987, gloves exams sterile medicine was at 16 cents a pair. In FY 1988 it was at 34 cents a pair.

CHAIRMAN WATKINS: It was what? What was this for?

MR. JOHNSON: Glove examination sterile. In 1987, it went from 16 cents to 34 cents. If you look at the small vinyl gloves, they were -- let's see, I'm trying to get the comparable --

CHAIRMAN WATKINS: Mr. Johnson, could you let us know for the record what you're reading from and how authoritative is the data? What are you reading from?

MR. JOHNSON: This is a document that my purchasing department put together for me about six months ago so that I could understand what the cost would be for just gloves. We then further expanded it by including goggles, aprons and a variety of other protective devices. This is an internal document. What the document shows that --

CHAIRMAN WATKINS: Could we have this for the record? Is this a problem for you to let us --

MR. JOHNSON: No, I'd be happy to provide this for the record. Yes, sir. I'll have to annotate it to make sense out of it, but I'd be pleased to do that.

CHAIRMAN WATKINS: I think one of the things I'm most concerned with is fairness. We need special attention to these issues, and we ought to have at least a national ethic that says, "This is not an opportunity for those of you to raise prices."

Now, if prices are going up with inflation or if there's additional quality control that had to be applied, you can understand reasonable profits. But we don't seem to have access to that. It seems to be clouded under "proprietary information". There doesn't seem to be a reasonable formula that says, "This is fair." You don't need to have all the data on the exact chemical construction process of a latex glove.

It seems to me you can have an audit firm that says, "Yes, they followed standard procedures, they have a reasonable cost margin and it's acceptable." Most of us would say, "All right, that's at least a marker laid down," and we know how to deal with the financing of it. Otherwise, we don't know whether we're pouring money down a rat hole, a profiteering rat hole.

I'm not saying there is profiteering, I'm just saying I don't know because we can't get the information to make a declaration. So we need your help to say, "We think it's unfair. If it's the same latex glove, what is it two and a half times what it was two years ago?" What have we done?

MR. YEZZO: Admiral, as an authority, I would reference the American Hospital Association, only because I think we all buy from the same group purchasing. No matter where we are in the country, we kind of buy off the same group purchase. We may all have individual needs, but AHA would probably have the most standard history of costs, I guess. No? They wouldn't?

DR. BOUFFORD: We do, because of public bidding -- I mean virtually everything we buy is competitively bid. I believe we could probably identify certain key items and what the relative manufacturers are offering up. I'd be happy to provide that to you.

CHAIRMAN WATKINS: This would be valuable. We're not going to solve every line item issue, but if we can raise the question of fairness, particularly for an emergency of this kind for the nation where we really want people to pull together and keep those costs down, do what's necessary to keep them down and keep them fair. It seems to me that's not an unreasonable position for us to take. But we don't want to make that kind of a statement unless there are good grounds to justify such a statement.

MR. YEZZO: And we'll ask the Greater New York Hospital Association to provide that data since they can give some idea on it.

DR. BOUFFORD: We'll send you something too.

CHAIRMAN WATKINS: All right. Good. Thank you very much.

DR. LEE: Mr. Chairman, I want to point out that Mr. Yezzo, when he talks about a four-fold increase in amphotericin and bactrim, these started off very expensive drugs. You're looking at thousands and thousands of dollars for one hospitalization on one drug. So, we'll let that drop for now.

In Texas, I'm a little bit familiar with Dallas. If you don't have any money in Dallas, you don't go to the private hospitals, correct?

DR. BURNSIDE: That's correct.

DR. LEE: You go to Parklands.

DR. BURNSIDE: That's correct.

DR. LEE: And you're losing, you said, $3 to $4 million on the AIDS patients?

DR. BURNSIDE: Yes.

DR. LEE: Where in the tax system is that picked up because you don't have any state or local taxes.

DR. BURNSIDE: Yes, we have a local tax. We have an ad valorem tax in Dallas County. Parklands Hospital annual budget is approximately $218 million a year. About 48 to 50 percent of that is from the tax base of Dallas County taxpayers.

DR. LEE: Is that paid out in the property tax?

DR. BURNSIDE: Yes.

DR. LEE: I see.

DR. BURNSIDE: That's an add-on, if you will, to property tax, which is why we're so concerned when the county commissioners alert us to the fact that there's approximately $10 billion in bankruptcy in Dallas County, which means that, depending on how the bankruptcy courts rule, whether or not they will be paying taxes which puts us at very great jeopardy in addition to all of the other dilemmas we have.

DR. LEE: So, from a political point of view, your people there have a big incentive to make some changes here --

DR. BURNSIDE: Yes, indeed.

DR. LEE: -- in that Medicaid coverage.

DR. BURNSIDE: Absolutely.

DR. LEE: Dr. Boufford, you said in your text here that there's 37 million Americans with no insurance. Where are you putting Medicaid and Medicare in there? They're not eligible for either one?

DR. BOUFFORD: For neither, no. Generally they are over the cutoff for Medicaid eligibility.

DR. LEE: They're over Medicaid --

DR. BOUFFORD: Or they're uninsured or underinsured, yes.

DR. LEE: 37 million?

DR. BOUFFORD: Yes. Some say the number is higher, but either uninsured or underinsured. And the other group would be people who are employees of small employers who provide no benefits or have part-time seasonal work.

DR. BURNSIDE: Or families of those who are employed but whose employers benefits only cover the worker and not the family. And migrant workers, young married couples, single entrepreneurs who are trying to get a business started and can't afford it.

DR. LEE: Right. Now, you people have sent in some super recommendations in here, but if we added them all up -- I'm not talking about the money right now, but if you added them all up, how many of those 37 million uninsured would be covered?

DR. BURNSIDE: If you just addressed the poverty level and Medicaid coverage, you clearly are going to be encompassing millions more American citizens who would have some access to the financing for their health care.

DR. BOUFFORD: If you could do something on the private insurance side with employers, either to assist the small employer to sustain a level of benefits and/or larger employers after disability, you would, I think, again help an enormous number of people.

DR. LEE: Okay. Well then, I guess what I would finish up with is we're trying to address those people that don't seem to be covered. Thirty-seven million is more than I thought it was.

Daniel Wartonick is the staff man that's handling this hearing. If you can look very carefully at your recommendations and add or adjust or whatever on those recommendations to see how many of those 37 million can we pick up. I noticed that the staff sent out a very nice form on how much it would cost and if you can give us any idea of what the total costs are, that would

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SerVAAS: I get a lot of mail from prisoners who worry about their health care in federal and state prisons. Some of them worry that they aren't being tested for AIDS and they worry whether they have AIDS. I checked with a physician who had worked with prisoners in the D.C. area just recently and he said that they didn't have enough money to buy AZT for the prisoners who have AIDS. They just didn't. He felt in his work in the D.C. area that they were afraid to test their prisoners because then they would be asked to give them AZT and they couldn't afford it because they didn't have the money.

I was interested in what he said. In view of all this conversation about the federal government, wouldn't the federal prisons be a good place to start in getting more help from the federal government?

Any of you who know about how the prisoners are really being treated. You can't always believe all the mail you get from prisoners. But I did check it out with some doctors who confirmed this who have worked with prisoners.

DR. BOUFFORD: The public hospitals in the city are responsible essentially for inpatient care in closed units. We also take the outposted patients from Riker's Island, which is the city correctional facility. I can't speak for state facilities.

I think it's fair to say that the prison health systems in most cities and most parts of the country are certainly not what anyone would like them to be in general. Then to superimpose a rather unusual group of people who become very acutely ill and some of whom go into long-term care is unusual for the prison health system and is something we have been facing in New York City.

In fact, we now have prisoners in long-term care beds in our long-term care facilities in the city, who cannot, because of the nature of the crime they've committed, be released on their own recognizance even though they are terminally ill. So they require a long-term setting with more medical support than can be provided in the prisons.

In the city system we have tried to put a program together that assures prisoners with AIDS the same kind of access to services, in addition they are eligible for testing at their own request on a confidential basis in the city's prison system. We're trying to mirror, at least, the services available to the general population, but I think what's done within the context of a prison health system could be a lot better.

DR. SerVAAS: Thank you.

MR. YEZZO: We at St. Clare's have a prison unit, but it's affiliated with the New York State Department of Corrections rather than the City. Right now we have 15 beds and we're going to be expanding that to 25. It's another ball of wax. It's a completely different theatre because you are not only as Dr. Boufford pointed out, dealing with a very complicated illness, but also the majority of the prisoners with AIDS are IV drug abusers. The manifestation of that virus in the IV drug abuser seems to create a whole other list of problems. Their care is multi-dimensional. Psychologically they are more unstable, and have a lot more problems.

I think New York State is probably one of the best in the country as far as states providing services for prisoners but there are problems. For example, in Sing Sing there are 2100 inmates. They claim to have six or seven prisoners per unit who are HIV positive. I would suspect that the number is more like 11 or 1200 of the 2100 inmates who are HIV positive. So you don't know who's not coming forward for fear of reprisal in the prison. If and when they have symptoms or are sick, how many prisoners are hiding and subterfuging those systems. So, I think the numbers are very large in the prison system in general throughout the country. People are afraid to say, "Hey, take a look at me."

DR. SerVAAS: Dr. Parrott mentioned about starting drugs early is helpful. It seems that the prisoners, would be an ideal group where you have a high incidence of AIDS to start drugs very early on if we knew.

You mentioned, Dr. Parrott, that now we're looking even at children for vaccines. We were told last week that in Africa they don't hold up mumps, measles and rubella now because it's such a devastating disease for these African children. But we don't give those vaccines to the babies in our hospitals?

My other question to you is, we do give children pneumonia and influenza vaccines that are killed virus vaccines and that is beneficial if it's done early. Is that right?

DR. PARROTT: Yes. You asked a series of questions, one about prisoners and the use of drugs. There's a dilemma there because many of these drugs are experimental. Some years ago, as many as 25, essentially prisoners who are not in a good position to give their own truly informed consent were excluded from most experimental drug or vaccine trials. So, there's a dilemma in that respect. I think as was alluded here, when a drug as AZT is approved for use, it shouldn't be excluded from prisoners.

My comments about early use of drugs was a bit predictive for children but we are hopeful that new drugs will be used for children. If, in fact, we found one that was not toxic, if AZT does not cause any damage to a fetus, maybe treatment of the mother during pregnancy would prevent her infecting the baby. That is a very attractive, although experimental, idea. So, the idea of early treatment falls in there.

Now, about the vaccines in this country. Just two weeks ago the CDC morbidity/mortality weekly reports recommended a change in the previous recommendations about the live measles, mumps, rubella vaccine on the basis both of what was observed in Africa but in this country, deaths in children who were HIV infected from natural measles, saying therefore that the risk from the attenuated or weakened virus is probably less than the risk of getting natural measles.

So, that was changed just a couple of weeks ago as a general recommendation in this country. And yes, it is recommended, although an HIV infected person is not likely to respond as well as a non-infected person. Their immune system is weakened.

The killed vaccines are recommended, as they are for other so-called high risk groups. Influenza, pneumococcus particularly are recommended for people who are at high risk for lung disease, heart disease and so forth, and now HIV infection.

DR. SerVAAS: To cut down the costs, wouldn't it help a lot in the federal prisons and all the prisons to be giving that vaccine, the pneumococcal vaccine and the influenza vaccine?

DR. PARROTT: These vaccines are recommended for anybody at high medical risk, not just children with AIDS.

DR. SerVAAS: If we aren't doing that in the prisons, that might be a place where we could really make some strides in prevention.

DR. PARROTT: Yes. Again, I assume when you're saying "in the prisons" you're saying it's a controlled population and we could make people do it. I'm not sure that's entirely true either. I don't really know myself what the situation is in the prisons. I tend to share what I've read and what I've heard here, that probably, almost surely, health care in the prisons in this country is not topnotch.

DR. SerVAAS: If you're to believe the mail, it is very bad.

DR. PARROTT: Incidently, you earlier alluded to D.C. I know that D.C. is doing in its prisons the same thing that New York is, offering voluntary testing. It has not reached the point that the federal government did for routine mandatory testing in federal prisons.

I don't know that AZT is not available. You implied that it was not. I don't know that it's not. We could find that out if you want to know.

DR. SerVAAS: I would like to know. Thank you.

CHAIRMAN WATKINS: We're going to have to close out this panel. We've kept you longer than we should have here.

We're going to have a representative from Bailey House here this afternoon, Mr. Yezzo, but I'd like to have just a very quick answer from your point of view to a couple of things.

How do we pay for the care of the homeless with AIDS? Two, where does a Bailey House, New York City, fit into the comprehensive care plan concept that you had in mind?

MR. YEZZO: Let me answer the second one while I think of an answer to the first part of that question. Bailey House has been a resource to all the hospitals in New York City, but it's been a very small resource, 45 beds, to provide housing situations for people with AIDS who can live in a home environment with some minimal support or no support.

CHAIRMAN WATKINS: And who pays for that?

MR. YEZZO: Well, Bailey House is supported by the City of New York on a subsistence program that they have developed. Dr. Boufford, I don't know what the amount is. Do you know?

DR. BOUFFORD: There's a Medicaid piece and a disability piece. It's paid through the Human Resources Administration. I'm not sure exactly of the mechanism. I know Medicaid is involved and the state Department of Social Services.

MR. YEZZO: But they have also packaged the financing very nicely. They've taken a piece from the city to provide ongoing types of support, but they've also have gone to foundations. Both the Robert Wood Johnson Foundation and Public Health Service have given money for establishment, renovation, and a lot of other things that they're doing at Bailey House. So, it's kind of a package deal that they've put together.

Again, what we're trying to do is establish two 18 bed residences similar to what they're doing at Bailey House, but out of Saint Clare's. But the two residences are just drops in the bucket. The numbers are just getting out of control.

For example, when another hospital, to go unnamed, heard that I was opening up two 18 bed houses in Manhattan for people with AIDS and HIV positive people who could live at home, they asked me if I was interested to condo them. Now, this is a hospital that was not designated as a comprehensive AIDS center so they were not getting an enhanced rate. As a matter of fact, they were getting paid on a DRG system that doesn't really adequately respond to someone being in your hospital for 25 or 30 days.

It would be cheaper for hospitals to own apartments, so to speak, by paying $20, $30,000 for an apartment and condo-ing it, which was an interesting concept and I haven't given them an answer yet on that one. But that's how badly off we are for apartment settings for people with AIDS, especially in those hospitals that are not comprehensive AIDS centers, because those patients are backing up. They have no idea of how to get them out.

CHAIRMAN WATKINS: And the projections for dealing with the homeless with AIDS, how does it look for New York State?

MR. YEZZO: A number that we had been dealing with was roughly 1,000 additional apartments immediately and then 500 additional apartments every year. Now, that --

CHAIRMAN WATKINS: Is that going to be forthcoming or is that one of these things that's a nice plan but really is not going to be executed?

DR. BOUFFORD: I think there's a special effort at this point to try to look at the numbers. The state of New York recently issued ICF regulations which are going to permit housing with supportive services in a more flexible model, the way Richie had described earlier, which will allow a vehicle that is better reimbursed, both on the capital side and on the expense side.

CHAIRMAN WATKINS: And that's all within the state or local authorities to arrange that, is that correct?

MR. YEZZO: That's correct.

DR. BOUFFORD: That's right. And any housing that's done at this point is generally without the federal support. It's through the state and local governments. The city pays 50 percent of any new housing that goes up and the state pays 50 percent. So, it's a much bigger hit than a Medicaid supported program like a health related facility such as New York State has proposed.

I think this is exactly the kind of dilemma I mentioned earlier where in a city that has tens of thousands of homeless families, how do you make the choice of who goes to the head of the line for housing: AIDS patients? mothers with children? These are the kind of issues we're facing when the responsibility is left at the municipal level.

MR. YEZZO: Admiral, when the State of New York put out the ICF regulations or even spoke about them, and again I must sound like a guy crying with two loaves of bread under each arm I was a bit disturbed that they were continuing to use old ways to describe what we wanted to do.

ICF regs, although we have to maintain a baseline of those regulations, they've blown some of the caps off the top of it in order to meet the needs of this population and giving you certain waivers, so to speak. But waivers can always be taken away. What I was trying to push for was a redefinition of that type of situation and the State didn't do that. But they did recognize the need for the houses.

CHAIRMAN WATKINS: Thank you very much. This has been a very informative and special panel. We appreciate your staying here longer for us to answer questions. Thanks very much. We'll recess now until 1:45.

(Whereupon, at 1:13 p.m., the hearing was adjourned to reconvene this same day.)

AFTERNOON SESSION

1:52 p.m.

CHAIRMAN WATKINS: We'll continue the hearings now with our first panel this afternoon, Financing Out of Hospital Care Alternatives.

We have with us Dr. Pamela Maraldo, Chief Executive Officer, National League for Nursing; Mr. Robert M. Crane, Vice President of Government Relations, Kaiser Foundation Health Plan; Mr. Steve C. Anderman, Deputy Director, Division of Health Care Financing, New York State Health Department; Mr. Paul L. Riger, Executive Director and Chief Executive Officer, Visiting Nurses Association of D.C. on behalf of the National Association of Home Care; Mr. Benn Brown, Associate Director, AIDS Resource Center and Bailey House.

Welcome to the Commission's hearing and we'll commence with a statement from Dr. Maraldo.

DR. MARALDO: Mr. Chairman, members of the Committee, Dr. Conway-Welch, I am very delighted to be here and I appreciate the attention and the emphasis that the Commission has given to the important component of caring for AIDS patients, nursing care, and I appreciate the opportunity to testify today.

I've submitted a lengthy statement for the record, but I will in the interest of time summarize my comments in four major recommendations.

With due respect to the very frightening and devastating nature of Acquired Immunodeficiency Syndrome, many of the problems that it presents in the delivery system are similar to many which currently exist and call for generic solutions which apply to all chronic illnesses -- that is, diseases which don't have a cure.

Primarily, we have predominantly chronic illness in the nation, and an acute care system based on a medical model directed at curing, which is increasingly inappropriate and ineffective in caring for chronically ill patients. Since the federal government is the largest purchaser of care, then the fundamental and far-reaching solution, I think, to deal with the AIDS problem would be to restructure the Medicare and Medicaid programs which place their emphasis on short to medium term hospitalization and short episodic treatments when the real need for coverage is for long-term care, in the home or in skilled nursing facilities.

I think home care should constitute the centerpiece of a newly structured Medicare system because it's less expensive, more comfortable, more humane. You've heard many of these reasons. However, a new structured public financing program should include managed care systems as well that would provide the most appropriate settings and the most appropriate providers for chronically ill populations.

So, my first recommendation is a fundamental restructuring of Medicare and Medicaid which I believe would be most furthering in caring for the AIDS population.

Secondly, since primarily chronically ill populations, including those with AIDS, require primarily nursing care, the nurse provider, we believe, should be paid, reimbursed, as a case manager who would be responsible for coordinating care across settings, following discharge from an acute care setting, and for providing comprehensive care.

I think redirecting Medicare pass-through monies to graduate nursing education which is eligible under the regulations currently written for reimbursement would be a very viable method of financing this provider. Positioning and reimbursing nurses as independent providers in the role of case manager would go a long way toward alleviating the nursing shortage as well, but that's another commission.

Number three, and I believe most importantly, because of the magnitude and the imminent threat to society posed by the AIDS problem and because we're unlikely to see a restructuring of our public financing programs in the immediate future, I believe that we should have a much more immediate solution. We recommend the establishment of a federal, categorical initiative designed to circumvent the current problems in the system to deal with this specific and threatening disease.

A federal AIDS initiative should be appropriately shaped to deal with the three most pressing problems related to the development of adequate financing mechanisms, that is continuity of care problems, the high cost and manpower supply issues.

Specifically, Congress should authorize a program of special project grants for individuals living with AIDS, to provide funding to community agencies to provide comprehensive care to AIDS patients. These services should focus on outpatient ambulatory services and have, as a centerpiece of the program, home care as a setting of choice.

Lastly, number four, mechanisms to recruit and retain qualified nursing personnel must be included in such a federal program. These mechanisms should address salary structure, should address funds for community education about AIDS, its prevention by nurses and to nurses and other health personnel. I'd be pleased to answer any questions and thank you again for the opportunity of testifying.

CHAIRMAN WATKINS: Thank you, Dr. Maraldo. Mr. Crane?

MR. CRANE: Thank you, Mr. Chairman. I'm accompanied today by Dr. Robert Lawrence who is the Chief of our Immune Deficiency Clinic in Portland, Oregon. He can deal with any of the clinical issues that you may want to explore.

Kaiser Permanente is a prepaid group practice program. As such, it organizes finances and provides health care services. We have had extensive experience with AIDS. The majority of our health plan members are located in urban centers where AIDS is very prevalent. In San Francisco, where a quarter of the population is enrolled in our health plan, we are second only to the county as a provider of care to AIDS patients.

In treating AIDS, we have learned that services can be provided in a cost effective manner. Indeed, this is essential if AIDS is not to overwhelm our health care system.

Prepaid group practice plans like Kaiser Permanente provide members with comprehensive benefits, ambulatory care as well as inpatient care. Most aspects of AIDS can be treated outside the hospital setting on an ambulatory care basis or through home care.

For example, we have set up an ambulatory infusion center in a number of our Regions as an alternative to high cost inpatient treatment. These centers provide outpatient drug therapy to a large number of AIDS patients who otherwise would require hospitalization.

In San Francisco, in the first 18 months of operation, the Center saved an estimated 3500 inpatient days. This not only conserves resources, but is the preferred method of treatment for many AIDS patients.

In a study in our Northern California region, outpatient costs represented about 30 percent of the $35,000 lifetime cost for an AIDS patient in our program.

Planning and organizing services and establishing more cost effective treatment modalities will moderate the cost of financing AIDS care. However, there remain significant gaps in financing this care. These are difficult to consider without looking at the broader problems of how to increase access to the 37 million Americans who do not currently have health benefits coverage.

Let me summarize our suggestions relating to financing of care. First, establish state risk pools for the uninsured. Fifteen states have established such pools with subsidized premiums. Other states should be encouraged to do the same. Pools should be financed with a broad base of revenue. If health plan benefit plan assessment is the mechanism to be used to finance such subsidies, the risk of preemption should be changed so that self insured plans can participate as well.

Second, increase employer provided health benefits coverage. Seventy-five percent of the uncovered are employed or dependents of workers. Incentives for employers or new requirements may be needed to accomplish this.

Three, expand Medicare eligibility. If reducing the 24 month waiting period is not feasible, consideration should be given to ways to coordinate Medicare eligibility with the current 18 month COBRA continuation requirement.

Fourth, encourage health benefits plans to cover and underwrite AIDS using similar rules. Concern about adverse selection by health insurers and health plans is likely to lead those plans to use underwriting and other means to avoid covering persons with AIDS. More uniformity in rules would remove this as a competitive issue among plans and expand coverage for persons with AIDS.

Fifth, examine the need for providing financing relief for health benefit plans who end up with disproportionately large number of AIDS patients. Such a safety net under plans would reduce plans incentives and activities to avoid covering persons with AIDS. It would keep more AIDS individuals in the insurance market and reduce reliance on Medicaid.

Finally, increase Medicaid coverage and payment for persons with AIDS. Extra payment for providers would remove disincentives for caring for them. In addition, there is a need for more uniform eligibility standards for AIDS patients across the states.

In addition, the Commission should consider ways to make financing less expensive. We have three suggestions. First, collect and distribute information about cost effective methods of care. Publicize what works. Infusion clinics, case management, mental health coverage as an offset to other costs, the most cost-effective drug therapy, all of these should be considered.

Also important is the consideration of treatment costs and methods relating to ARC and those who have been diagnosed as HIV positive.

Second, encourage health benefit plans to improve outpatient coverage. We have seen that coverage influences practice patterns. The Commission could do a lot by encouraging more coverage of care in low cost setting of care.

Finally, encourage community action in support of outpatient and home health care. San Francisco is a model in this area. How can that model be mobilized elsewhere? I think federal and state leadership and funding is necessary to create infrastructures in communities where volunteers and a broad array of community resources can be pulled into the care process and, in that process, reduce medical care costs.

There are obviously no easy answers here. I'd be happy to answer questions about any of the proposals which we have made.

CHAIRMAN WATKINS: Thank you, Mr. Crane.
Mr. Anderman?

MR. ANDERMAN: Thank you. I had a chance to sit and listen to some of the testimony this morning, so I know you've heard a lot about New York's comprehensive care model. I'd like to describe to you briefly how we've developed the financing structure around that.

One of the principles of the financing structure was the approach that we've taken to designated care centers. We have about 17 of them throughout the State of New York. One of the primary roles of those designated care centers was to serve as the locus as well as the case management tool to provide a continuum of care throughout the system, the first and only diagnostic groups for AIDS patients for the non-medicare population which are paying.

We also have given the hospitals an opportunity, if they would like to, to be considered as exempt units paid for on a per diem basis. Currently, those run between $600 and $900 a day and on a case basis at about between $11,000 and $16,000 per admission.

One of the other interesting things that we've done with the designated centers is we've restructured the outpatient financing program. What we've done is we've developed a pricing system which has roughly seven or eight different types of visits associated with that to try to encourage the hospital to be able to discharge a patient to an active outpatient program.

One of the visit types that we have is a comprehensive visit where a physician would work up a patient. One of the Commission members asked, "What if they present themselves in an emergency room?" Hopefully, an AIDS patient can come into an outpatient area in a designated center, get a comprehensive work-up, and then there would be subsequent intermediate care or follow-up visits as well as if the patient needed chemotherapy or blood transfusions or subsequent meetings with a counselor and a case manager.

We have all of those levels of different care needs defined, serviced, and priced. They range from about $40 a visit to, on a comprehensive work-up, about $250 a visit. At the same time, to provide this continuum of care, we have now a need of between 500 to 800 long-term care beds for AIDS patients in the state.

We have a very unique financing program for geriatric patients in this state called "resource utilization groups." RUGS is the acronym. It defines levels of care needs for patients without really a need to designate a site for that patient. These 16 levels of care that we have range from patients who we call "physical patients," who need just physical geriatric care, to clinically complex patients who need rehabilitative care.

We've looked at that system and said, "Can we adapt, given our comprehensive care and designated center approach and our case management approach, can we retool that RUG system to fit in the model that we're trying to do?" Well, we did. We just released regulations to that, and we priced out what it would cost to care for AIDS patients in these settings. The range there goes from anywhere at the low end of about $100 a day to the high end, some of the clinically complex patients or the special care patients as we call them, to about $250 a day.

The other piece that we have done is we've also as a continuum looked at home care, the home care patient. In association with our home care association, we looked at costing out what the AIDS home care patient would cost. What we found when we did that is a couple of things. First, the initial visit took longer for a nurse -- I'm talking about the nursing visit -- than looking at the typical type of home care patient that the home care agencies in our state take care of.

We also saw, given the fact that we put in a regulatory case management effort, that the case management time naturally was longer. What we've done in the home care, and our regulations are in effect, we've structured a home care payment system that recognizes an increased payment. In different areas of the state, it's roughly between $60 and $90 a visit, which is about 30 percent higher than the typical home care patient. That's proven out because of the time studies that we've done. That is in place. So, one of the major obstacles that we are dealing with now -- in fact, there have just been meetings on it in the last couple of weeks -- is trying to find the capital

funds to develop some of the non-hospital based settings. In meeting with investment bankers, the word that they gave me is unless there is security, meaning either some kind of overlaying insurance or some state security or back-up agreement or as we sometimes call it, moral obligation agreement, they really weren't interested in doing business or giving us the capital dollars to get some
of these other plans, non-hospital based plans and home care and other things up on line. So, that's been a little bit discouraging. We are working to try to get around it.

My suggestions really for the Commission are a couple. First, as Mr. Crane has said, the waiting period on Medicare, something needs to be done about that in order to get patients to become Medicare eligible. If we do that, you also have to be very careful, as you define some of these other layers of services, to get at the coverage issue. Because, Medicare only covers -- in the long-term care area, for example, if a patient is "rehabilitatable." That needs to be looked at as well in terms of coverage.

As my colleagues said this morning, I'd like to see a greater federal match on the Medicaid patient. In the State of New York, it's roughly 50 cents on the dollar for the feds, 25 state and 25 local. In the long-term carrier, the state because of trying to provide property tax relief several years ago increased our share of the long-term care business to pick up that.

And I would also, lastly, to try to be able to get some of these other alternative sites and plants, physical plants up on line, I'd like to see some dollars available for some seed money for capital so I could go to the investment bankers and basically structure either some type of insurance arrangement or some type of secured loan program. Thank you.

CHAIRMAN WATKINS: Thank you, Mr. Anderman. Mr. Riger?

MR. RIGER: Ladies and gentlemen, the National Association for Home Care, on whose board of directors I serve, represents the interest of nearly 6,000 home health care providers, including hospices and homemaker home health aid organizations.

The home care industry has been an important player in the design of a cost effective and humane system of care for persons with AIDS from the early days of the epidemic when it became apparent that hospitalization as the major setting for care was costly and often unnecessary.

Home care's role in the care of patients with AIDS may have emerged for economic reasons, but home care is particularly appropriate for persons with AIDS because home care enables persons with AIDS to spend their remaining days in familiar surroundings providing emotional support for them and their families. Home care provides maximum independence and dignity and home care significantly improves the quality of life for persons with AIDS and provides the opportunity to maximize the use of their remaining time.

Home care also allows the greatest opportunity for family members and significant others to become educated about AIDS and to participate in the care of a person with AIDS. Home care allows for the use of an appropriate continuum of care based upon the least restrictive setting. And finally, home care may cost substantially less than institutional care for appropriate patients.

Although we have limited national figures on the cost of home care in AIDS, data from the AIDS Home Care and Hospice Program of the Visiting Nurse Association of San Francisco, and the AIDS Project of the Visiting Nurse Service of New York, as well as our own experience here in Washington, D.C., provide a good estimate.

San Francisco VNA states that the average length of stay in their program has been 57 days from the start of care through discharge. Ninety percent of the patients have died at home. The average cost per patient day in the program is $94, or approximately $5,358 dollars per length of stay. In 1984, the San Francisco program had an average daily case load of 18. By 1987, the case load had increased to 63.

The Visiting Nurse Service of New York calculates their per diem costs for 1986 as $81.40. Their program supports a Medicaid contract with New York City. The Visiting Nurse Service of New York has contracted to provide all of Medicaid's services as well as home attendant services and continuous nursing services. In 1985, VNS of New York had an active case load of 56. By May of 1986, there were 249 patients receiving care. Since the initiation of the Medicaid program, New York Visiting Nurse Service has received referrals on 1,255 infants, children, and adults, and an additional 1,250 patients from other sources.

Here in Washington, we served 32 AIDS patients in 1986, and 75 in 1987, with an average cost per case of approximately $1,300, 90 percent of which was reimbursed by Medicaid and only eight percent private insurance. As has been stated earlier, Medicaid reimburses substantially below the cost of providing service, which creates a dilemma for the provider.

Home care for AIDS patients is not without its problems. Many patients who would be eligible for home care

are homeless. Therefore, institutionalization is the only option for care. In addition, the nation is experiencing a nursing personnel shortage, including registered nurses, licensed practical nurses, and homemaker home health aids. It is this shortage factor that contributes to the higher utilization of institutional care and subsequent higher costs in New York City.

Inadequate financing, of course, contributes to the shortage problem. Homemaker home health aides can make more money working for McDonalds than they can providing care for those in need. Medicaid rates do not allow for adequate reimbursement of these vital components of the health care delivery system.

As the demographics of the AIDS population shifts from the male homosexual community to the drug abusing population, the number of uninsured and under insured patients has increased. This has placed a terrible burden on public hospitals, public health home care agencies, and voluntary agencies such as visiting nurse associations. These organizations must accept uncompensated care, and while the volume of uncompensated care has increased dramatically, reimbursement and funding through contributions and other sources has not increased commensurately.

As has been mentioned earlier, very few AIDS patients are eligible for Medicare, because they have not reached the end of the two year waiting period, and Medicaid offers only a partial solution. In many cases, it does not cover the scope of the services required by AIDS patients.

It must be kept in mind that 18 percent of Americans have no insurance coverage whatsoever, including Medicaid, and the proportion of poor Americans covered by Medicaid had declined from 65 percent in 1976 to only 38 percent in 1984. Private insurance when it exists is similarly limited, and in some cases will not cover home care, which is at least a mandated service under Medicaid.

In light of these financing problems, the National Association for Home Care is quite concerned when pronouncements are made by federal policy makers that home care and/or hospice care is the answer to cost effective care for AIDS patients. Certainly, home care is part of the solution, but that solution must be predicated on adequate financing regardless of the setting.

Thank you for the opportunity to present our concerns. I will be happy to answer any questions that you might have.

CHAIRMAN WATKINS: Thank you, Mr. Riger. Mr. Brown?

MR. BROWN: Admiral Watkins and members of the Commission, my name is Benn Brown. I'm the Associate Director of the AIDS Resource Center of New York City. We're the sponsoring agency for Bailey House and the Scattered Site Apartment Programs.

We're the largest provider of supportive housing for homeless people with AIDS in the United States. Currently, we provide housing and supportive services to more than 65 homeless people. In our last year, we have provided residence for over 220 individuals and families. This number, in fact, is very small in comparison with the growing number of homeless persons with AIDS and AIDS-related conditions.

Private funding started our agency and provided us with our first apartments, but the demands for the private sector support are greater than ever. Public funding from government agencies is and must continue to be the major source for maintaining and developing housing for persons with AIDS.

Our funding has a variety of sources. Our operating cost at present in the Scattered Site Apartment Program are $42.50 for each individual resident and $106.25 per family unit per day. At Bailey House, which is a 44 resident facility on Christopher Street in New York City, the cost is $94.44 per day. These costs clearly demonstrate the efficiency of supportive housing versus the estimated $750 to $1000 per day of New York City costs for extended hospitalization.

In New York City, our requirements by contract are that each resident of the Bailey House Program pay $346 of their $425 SSI entitlement toward their room and board. This leaves the resident with approximately $79 to cover all their personal expenses for the month that Medicaid does not cover.

At present, there is no SSI level II funding source available to persons with AIDS due to the category of licensing which is a prerequisite for SSI level II entitlement. This is a critical concern for our agency and others trying to provide assistance to persons with AIDS. It is imperative that the Social Security Administration review its policy in the face of this national health crisis and direct state licensing authorities accordingly.

At present, there are no Medicaid, Medicare funding streams available to include capital or operating expenses for supportive housing. There were no accessible funding sources for housing when our agency began its work in 1983. We were the front runner of the race, and we have pieced together our funding on an ad hoc basis. In order for there to be replications of Bailey House and the Scattered Site Model Housing Programs, funding streams must be created which do not now exist.

No one should have to reinvent the wheel in order to provide services and housing for homeless people with AIDS.

We have four recommendations that we would like to make to you as a Commission. Our first recommendation is that there be a form of licensing created enabling group residence for persons with AIDS that would make them eligible for SSI level II funding. Our recommendation would be to attach the licensing requirements to the support services that are provided, rather than to the physical facility.

Second, we recommend an increase in the SSI personal allowance entitlement for residents to an amount suitable for a younger, chronically ill population rather than the current standards established for a more immobile, institutionalized population.

The third recommendation is that the U.S. Department of Health and Human Services issue a directive to state governments requesting that states develop a new licensing category for specialized residences for persons with AIDS and AIDS-related conditions. Only a small portion of persons with AIDS, the national average is actually less than ten percent, require medically supervised care on a continuing basis. A non-institutional housing environment is the most appropriate and cost efficient residential alternative to extended hospitalization.

Fourth, enabling legislation must be drafted to provide operating and capital funds for residences for people with AIDS and/or others with chronic disabling conditions in need of supporting housing, using the current community based models in place for the developmentally disabled.

Bold steps are needed in response to these issues and these recommendations. Housing and supportive services for the increasing number of homeless persons with AIDS is not only humane, but cost effective.

Over the past three years, the AIDS Resource Center's two housing programs have proven to be a life-enhancing alternative to institutional facilities. We have been able to provide to homeless people with AIDS a sense of home, a place of quiet where they can rest, a room with a door that they can lock at night when they go to sleep, a window with a view of a world that's not quite what they wanted it to be, but most of all a reassurance that people do care. Government action is necessary to create necessary funding and administrative means to develop and operate similar programs nationwide. We cannot afford to delay action any longer. Thank you for your time, and I would be glad to answer any questions.

CHAIRMAN WATKINS: Thank you very much, Mr. Brown. Let's start the questioning with Dr. Lee.

DR. LEE: Mr. Brown, as you may or may not know, I've had a special interest myself in Bailey House. I hope that you and Doug Dornan, who is the head of it, will give us everything you've come up with in the way of really specific recommendations for how we can create some kind of funding streams for you. I know we've gone into the Medicaid waiver issue, but anything that's specific that you can possibly come up with, please submit it to our staff.

MR. BROWN: Be glad to. In fact, tomorrow there's a housing conference in New York City that our agency is providing for other agencies that are trying to begin the program.

DR. LEE: Mr. Anderman, I must say I was a little confused. When you say, "we" are paying this and we are paying that, who is "we"?

MR. ANDERMAN: I'm referring to Medicaid.

DR. LEE: Medicaid?

MR. ANDERMAN: Medicaid.

DR. LEE: Now, $250 for a comprehensive health exam from Medicaid?

MR. ANDERMAN: A visit in the designated centers in the outpatient areas, yes. As part of being a designated center, we've restructured the outpatient reimbursement streams.

So, the $60 a visit that you heard earlier mentioned does not apply for AIDS designated centers. This has been part of the model, and so the reimbursement streams have ranged from a kind of a follow-up counseling type of session where it's roughly priced at about $45, to where somebody presents themselves and says, "I'm seropositive," and a complete comprehensive work-up is done. That's priced at about $250, $260 a visit.

DR. LEE: Now, you had quite an interesting idea there, going to private sources and financing your own insurance in some way? Is that what you had in mind?

MR. ANDERMAN: Well, we have a model that we built on -- and I don't know if you're familiar with trying to rebuild some of our hospitals which are in areas where there is a tremendous amount of medical indigence. We have a capital pool that we've put together in the state that we've used to develop an insurance mechanism and we're looking at that structure.

You have testimony coming down from Matt Scanlon, who is Deputy Director of our Medical Care Facilities Agency. We're looking at some models to try and kind of structure that financing. Part of the problem, though, is either the state's got to put dollars up or the federal government's got to. Somebody's got to create the security that the investment bankers want to have in order to go out and sell the bonds to the bond holders.

So, we're all kind of saying the same thing. Somebody needs some seed dollars to create an insurance mechanism or insurance pool.

So, yes, we've done it with two hospitals. We're going to be doing it with a third this year.

DR. LEE: Why would an investment banker give you money for this?

MR. ANDERMAN: They won't now. They won't right now, because there's no security. What we're doing is we're saying the capital dollars and capital flow will come in through the third party payer rates, Medicaid, Blue Cross, commercial, and Medicare. In the out-of-hospital settings, you're dealing with either all Medicaid patients or indigent patients. I did not mention that most commercial and Blue Cross plans generally don't have very good coverage on out-of-hospital alternatives. Very few have long-term care coverage. Very few have a minimal amount of out patient coverage. And so, the investment community is very reluctant to put dollars up because of a security issue.

DR. LEE: Would a "Big Mac" approach --

MR. ANDERMAN: Well, the Big Mac approach has got state sales tax dollars pledged behind it. So the answer to your question is, yes, somebody has got to sit behind and pledge behind the dollars so that if there's a default there's a mechanism there to pay the bond holder off who's holding the mortgage. That's part of the obstacle that in any of these programs you have to solve in order to get them up and on line. I'm sure housing and some of these others are no different than the medical model.

DR. LEE: It seems to me that might be quite an inventive approach in these days of serious budget problems in Washington.

MR. ANDERMAN: Well, the hospital program that we built is built on a tax that we tax the hospitals. We tax the premium payers in the State of New York. It's part of our bad debt and charity care pool, which amounts to about $400 million plus. This works out to about a $14 million or $15 million a year that gets set aside for what I've termed the "secured loan agreement."

So, it's $14 million a year that basically builds the security for the investment in the institution.

DR. LEE: Forgive me, but as a taxpayer I'm trying to get away from the tax.

MR. ANDERMAN: I understand that, but in order to rebuild about four or five indigent hospitals in the State of New York with the investment community not willing to do that, we had to come up and invent this vehicle.

DR. LEE: It sounds interesting. Dr. Maraldo, you had a couple of interesting things I wish you'd elaborate on a little bit more. The first is this categorical initiative thing. Reading what you say here, I don't understand what financial stream you're creating here that's different.

DR. MARALDO: Well, we're not really advocating that a new stream be created, just advocating that since most of the money that's gone into dealing with the AIDS problem has gone into research, that it seems to be a more immediate solution to a very pressing problem to designate some federal funds to flow through existing community-based agencies primarily to deal with the problem because of the Medicaid limitations in Medicaid eligibility, because of Medicare's limitations, and also because it's an urgent problem.

I know that it's not very popular these days when everybody's worried about our economic situation, but nonetheless I think there's a lot of reason to be wary about private sector solutions. There's a report that just came out in the end of February from the Office of Technology Assessment, and I think it's commendable what Kaiser has done and the Blues are looking at a managed care approach. But, I don't think there's any concrete reason to believe that it will be any more successful in managed care markets than we've been in indemnity markets.

In addition, it appears that from the report most insurers are treating AIDS like any other serious illness, and that is most serious diseases are uninsurable. So, I think -- it might sound simplistic and it might sound Quixotic in these economic times, but I think a federal categorical program modeled after the programs in the '60s and '70s would be the most expedient approach to stop the hemorrhaging.

DR. LEE: But, what are you talking about? I mean, what money is being created?

DR. MARALDO: Okay. I'm talking about special project grants that would be designated to specific agencies that could be selected in states as the primary agencies -- it could be on a competitive basis -- that are caring for the most part for indigent AIDS patients. Or, most cost effectively for patients, usually that's a home care setting or a day care setting. It's an out-patient setting.

DR. LEE: So, you're talking about grants coming through HHS or whatever?

DR. MARALDO: Pretty much.

DR. LEE: Okay. Now, the last thing was you had an interesting thing here about posing the nurse as the primary provider and have her following the case through and so forth. Develop that a little bit. Is that feasible in these days of no nurses? I mean, you've got fewer nurses than you do doctors, don't you?

DR. MARALDO: Yes, we do. But, I think that this would be most effective, not only in dealing with the problem of chronic diseases in the system, but I also think it would be a mechanism to attract more nurses into the system.

We've done a lot of studying of this problem over the years, and the autonomy issue is a central issue. I think that it's also been demonstrated that nurses in primary care situations are lower cost providers. They enjoy practicing independently and they're prepared to practice across settings. So, I think that it might kill a couple of birds with one stone.

DR. LEE: It's an interesting solution.

DR. MARALDO: Thank you.

DR. LEE: Thank you, Mr. Chairman.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: I'd like some more information, Mr. Brown, about the homeless that you treat. I know a little bit more about the people for whom you provide housing than I do about how you cope with the homeless.

A couple of hearings ago when we were in San Francisco, we were told there that the best estimate that anyone could come up with of the number of homeless people with AIDS in San Francisco -- correct me if I'm misquoting this -- was 200 to 600, which was a horrifying number. I'm wondering how you deal with homeless people, and in New York is it the same magnitude of problem?

MR. BROWN: The off-the-record estimate in New York, because New York City is still documenting officially, its homeless AIDS count is that on any given day there are 600 or more people in the City of New York who are homeless, who have AIDS, who would be eligible for our housing program if we were a larger agency and had the housing to provide for them.

Our current contractual obligations are that the people that become residents in our program are medically able for discharge from a hospital in the New York City area and they have nowhere else to discharge to except to the street. Then, by meeting those city criteria, we then do an intake with them to make sure that they're suitable for living in a community environment.

DR. LILLY: So, how in the world do you select among these people to fill the totally inadequate number of spaces that you have to offer?

MR. BROWN: We never have a problem in trying to fill a bed.

DR. LILLY: No. I know you don't have a problem. But, don't you have to -- do you have criteria for choosing among the people who want housing?

MR. BROWN: The criteria is that we have two alternatives. We have Scattered Site Apartment, which are the people who are in a terminal stage of the disease but are still self-care capable and very ambulatory. They can pretty well provide for themselves in an apartment with minimal supervision on a day to day basis by our staff.

People who are more medically dependent on food, more support services, we try to place them in Bailey House which is a 44 resident facility. All three meals are provided. Support services are provided around the clock. There's more supervision of the residents in that program.

DR. LILLY: Okay. Are these people who have become homeless because they have AIDS, or who were homeless and then developed AIDS?

MR. BROWN: Both.

DR. LILLY: Both. Roughly equal proportions?

MR. BROWN: The percentages are probably pretty well split. I would say right now our current population is about 60 percent homeless prior to diagnosis, 40 percent homeless after diagnosis.

DR. LILLY: I'd like to know a little bit more about how you raised the money for the operation. Your summary statement was that you depended on private money to get going and to sort of qualify you for public support. Could you elaborate a little bit on that?

MR. BROWN: It began as a small organization of business people and clergy in the West Village of New York City that created the organization and got the first two apartments. From that point, the apartments began to expand. We then made application to the City of New York for a contract to provide housing for homeless persons with AIDS. That was the first source of "public funding" that we obtained.

Since that time, we are a part of the New York City AIDS Service Delivery Consortium, which qualified us for part of the DEMO grant from the U.S. Public Health Service, which is a three year DEMO grant. We also qualified for part of the money from the Robert Wood Johnson Foundation. We have a DSAS grant through the Department of Substance Abuse of the State of New York. And we are currently seeking corporate foundation support.

DR. LILLY: At the current time, what percentage of your operating budget is from government sources, federal, state, and local?

MR. BROWN: All of our operating budget for the Agency, 23.5 percent is private dollar, individual. Everything else is either contract, foundation, or federal.

DR. LILLY: All right. Let's see. Well, I pass. I may want to come back.

CHAIRMAN WATKINS: All right. Mrs. Gebbie?

MRS. GEBBIE: A couple of different areas I'd like to explore.

First, Mr. Crane, some states I know buy pre-paid coverage, such as from Kaiser, for some categories of Medicaid eligible individuals. In Oregon, it's mothers with dependant children. Do you have any experience in any of your locations with groups that might include HIV-positive or ill persons for whom Medicaid coverage has been purchased?

MR. CRANE: Yes. In a number of regions we do. In both Northern and Southern California regions we have Medicaid contracts. One of the interesting things that California has done in the past year is to establish a higher level of per capita payment for beneficiaries with AIDS as an incentive for pre-paid health plans, as they're called in California, to take

AIDS patients or at least to remove the disincentive. So, we have programs in both the California regions and we have one in Oregon as well, and a number of other states.

MRS. GEBBIE: That higher rate is necessary? They consume more care than your average enrollee?

MR. CRANE: Yes, considerably more.

MRS. GEBBIE: Is that something that is being pursued by other states, do you know, or other areas?

MR. CRANE: Well, I'm not sure about other states, but in my written testimony we talked a little bit about the California model and suggested it as a way in which states can encourage managed care programs to care for these individuals. Once in the managed care program the Medicaid-eligible AIDS patient is more likely to get a proper mix of services, an emphasis on ambulatory and home care and a deemphasis on institutionalization.

MR. ANDERMAN: Could I just add something?

MRS. GEBBIE: Yes.

MR. ANDERMAN: In the design of the New York program, one of the things that's difficult to do, especially with providers, when you do a pre-paid or capitate arrangement, you're asking people to go at risk. And with this population and with the changes in care and the changes as you heard this morning about pharmacy costs and costs going this way and that, providers are a little reluctant to go totally in a pre-paid arrangement yet.

That's something that we are looking at about trying to do a managed care and a capitated arrangement for a Medicaid population. But, folks are reluctant for a lot of the reasons that you've been hearing about.

MRS. GEBBIE: But, you've been willing to do it, at least with the slightly higher rates, or lots higher rates?

MR. CRANE: I can't tell you precisely what the difference is, although I'd be happy to furnish that to you for the record if you would like. We have Medicaid contracts and some of the individuals under those contracts either have or get AIDS. As far as our program, we don't differentiate among them, although the government does differentiate among them in terms of payment amount.

And so, it's helpful to all the plans that have MediCal or Medicaid contracts to receive increased reimbursement. For the same reason that Mr. Anderman gave, when you have an AIDS patient, you have some certainty that the costs are going to be higher. It's just a fact.

MRS. GEBBIE: Yes. The reason I'm pursuing it a little bit is that we've heard a great deal today about problems under Medicaid. I don't want to put words in your mouth, but it sounds like under present Medicaid rules if a state is willing to pay your rate, that package of services that patients have been telling us they want is in fact available. Is that your impression?

MR. CRANE: I think that's right, yes.

MRS. GEBBIE: I'm looking also to Mr. Anderman, who's a purchaser. Is that --

MR. ANDERMAN: Again, I don't want to put Bob on the spot, but ask him if he had 5,000 AIDS patients.

MR. CRANE: Five thousand AIDS patients?

MR. ANDERMAN: Yes.

MR. CRANE: Well, I think --

MR. ANDERMAN: It's orders of magnitude.

MR. CRANE: That's right.

MR. ANDERMAN: It's orders of magnitude. If you have 10, 20, 30 patients and all of a sudden a lot of them convert and are seropositive and have AIDS and require hospitalization and the continuum of stream of care, this is the problem. On a capitated arrangement, the question is who's carrying the risk. Is it the provider? Is it the State?

Who's going to be the ultimate deep pocket if it does turn out that in Kaiser's case all of a sudden that patient needs AZT? AZT costs of $9,000 a case wasn't built into the actuarial premium that determined his payment. You're going to be careful and you're going to look at your mix and all the other types of things that you do in that line of business.

But, we have some Medicaid pre-paid programs up, but they are not actively trying to enroll this population. They are enrolling the population because of the conversions and what you have heard about in the testimony this morning with the AFDC case load and the mothers and infants, mothers becoming seropositive as well as the increasing number of infants.

MRS. GEBBIE: So, they're going to have some one way or the other.

MR. ANDERMAN: It's going to happen.

MRS. GEBBIE: Did you have something else to add?

MR. CRANE: If you're heading to a point where one easy solution to this is to take all those in Medicaid who get AIDS and put them in managed care, you would have a problem unless there was a substantial increase in reimbursement. Even then an HMO will want a balanced membership and may have capacity problems.

But, I think you are right that in those systems of care the Medicaid beneficiary is more likely to get a cost effective array of services and that overall that will cost the system less. Most plans would want a balanced membership, however.

MRS. GEBBIE: I'm quite convinced there's no single point solution to any of this. The other area I think it would help all of us to hear discussed -- and I think this may take several of you -- we've heard at various points in time, concerns about doing some things that would fix the Medicaid system. And then, we've also heard people express concerns about speeding up enrollment in the Medicare system for a person with AIDS or who is HIV positive.

I sometimes think the real reason for pushing enrollment in Medicare is the protection of the state dollar. Because, in fact, mere enrollment in part A of Medicare leaves you uncovered for several critical services, including drugs and some long-term benefits and I think some out-patient benefits that would otherwise be covered if you were on Medicaid.

So, as I think about it, maybe that's a false solution. It just sounds simple, and it maybe sounds appealing from a state legislature viewpoint. Maybe fixing the Medicaid side is better with one or all of those three things we heard about earlier today of broadening the services, increasing eligibility, paying a fairer share, which also has some appeal because it's a mixed state/federal solution. But, maybe I've lost something in the twists and turns of this argument. Could somebody --

MR. ANDERMAN: No. I don't think you've lost anything. The Medicare program is 100 percent federal dollars. If you drop the eligibility and now somebody is eligible for Medicare, in-patient hospital stay in our state is about, at last estimate and going up, is about $335 million out of a half a billion dollars in terms of care being provided. So, there's $335 million that is a number that is being increasingly borne by state and local government that's going to go increasingly in the federal share.

You're right. You could do the same thing, perhaps, by saying, "Well, we'll take over for AIDS patients like we did for kidney disease and end stage renal disease, the care for those specific patients." So, that becomes 100 percent federal dollars. There are very few Medicaid dollars in kidney dialysis, because you took it over. The federal government took it over years ago.

Your logic is not off. It's basically looking to relieve some of the state and local dollars to a more national basis as opposed to particular areas, particular communities, and particular regions in the country bearing the brunt of AIDS.

MRS. GEBBIE: But, from the point of view of the patient, the person who's sitting here trying to figure out how to get care and miserable because of Medicaid because they happen to be in a state that might not do anything right for them -- and, therefore, hearing all this testimony thinking Medicare is going to be my answer, if we simply put the person in regular Medicare --

MR. ANDERMAN: I agree.

MRS. GEBBIE: -- will I be just as disappointed because I'll suddenly find a bunch of bills arriving on my doorstep? I see some heads nodding. So, it would be --

MR. ANDERMAN: I'm agreeing with you, yes.

MRS. GEBBIE: -- more than just, if we were going to go that federal route, because we decided we didn't want to leave the burden with the states. We would not only have to, say, make eligibility available earlier, but make it cover a wider range of services in some way?

MR. ANDERMAN: Absolutely. You have the eligibility question and you have the coverage issue. I mean, take Medicare long-term care services. In our state, 85 percent of the long-term care business is Medicaid because ultimately people spend down and become Medicaid eligible or they exhaust their private resources when it costs $30,000 a year to be in a long-term care facility in our state.

So, if the Medicare coverage now says, "We're only going to cover patients who are rehabilitative patients," and an AIDS patient, although maybe requiring some rehabilitation, may have dementia issues and may have some other issues, Medicare could turn around and say, "This patient's no longer Medicare covered." And then, the whole process starts all over. You spend down and then you become Medicaid eligible again. Yes, I think you're on the right track of a combination of issues related to coverage, eligibility and matching programs. So, it's a combination of all three.

If you want to put an immediate patch in the hole in the dike, you make everybody Medicare eligible and then you take the load off on the in-patient care side.

MRS. GEBBIE: Except that we've been trying to get people out of the in-patient care setting. So, we've still left the load in that part of the setting where we really want to push care.

MR. ANDERMAN: That's right. And you still have all the issues that you pointed out correctly on part A and part B of Medicare, which have some gaps that you hear about all the time that geriatric patients face.

MRS. GEBBIE: Because this hasn't been talked about in this context before, I think it would be very helpful to the Commission if one of you or a couple of you who are particularly knowledgeable about these systems might just sketch out for a typical patient what would and wouldn't be covered, say, in New York today, if suddenly your typical AIDS patient went on Medicare, from what you're getting now under your state Medicaid program. I think too many people have held out Medicare as a quick fix and it's clear to me the more I listen that it simply opens a different set of problems to be addressed.

MR. ANDERMAN: Yes. I think it's basically the hospital, the in-patient hospital benefit, perhaps some long-term care, and perhaps some home care.

MRS. GEBBIE: Yes.

MR. ANDERMAN: And then, you're going to run out.

MRS. GEBBIE: And so, you'll be back to the state Medicaid system, which may still not take care of home care benefit or certain long term care benefits and then you're back to some of the issues you heard this morning.

MRS. GEBBIE: I'll stop for me. Thank you.

CHAIRMAN WATKINS: Mr.DeVos.

MR. DeVOS: Earlier today we were discussing the moving population, how people move towards certain areas where, perhaps, they get better care. Mr. Anderman, if you can find all these nice new housing units, would you use it to attract a lot of other people to your state, increase your costs? Is there a better way to care for people at a lower level of costs in other settings or is that -- everybody screams at me when I say that. I say, well you can't ask them to move away for better care, but at the same, if they're homeless and the costs are very high in New York --

MR. ANDERMAN: It's also, I'm sure --

MR. DeVOS: And so you attract people.

MR. ANDERMAN: -- it's also hard to find property in New York City, too, that you can build something on.

MR. DeVOS: So you attract people? You don't have any idea how many people who really live elsewhere?

MR. ANDERMAN: No. I heard you answer the question. We would have the data probably for '87 and I can go back and ask the people in the AIDS Institute, at least in the in-patient hospital setting. I would be able to get the data for people who are coming in and receiving services, because we collect data on hospital admissions in the state.

MR. DeVOS: It's just if there's the inconsistency of some states doing virtually nothing, and some of their citizens may well have migrated towards some other place. The burden on a city like New York or the state of New York just goes and on and on, and New Jersey. It's staggering.

What are you going to appeal to those other states and say, "You owe us something?" Is there some way to say, "Wait a minute. This guy worked and paid taxes in your state for years. Now you got to come in and kick in a little bit on this bill." I know that's not the way it is today. But, you know, if you keep providing the way you are, you're attempting to, it will be expected of you. People out in the country don't really care much sometimes.

MR. ANDERMAN: As we got the hospital program up and seeing that we had problems there, we're turning our attention to long term care and to home care and trying to restructure at least from my responsibilities the financing programs, the financing programs there. I think the issues related to the housing and some of the dollars that are available to that don't even fit into Medicaid because Medicaid's a health insurance entitlement and the needs of some of these patients are greater than that. So anything you might be able to do creatively in a Medicaid program, which we're trying to do, you then reach a point where it falls off.

MR. BROWN: Mr. DeVos, if I could speak to that issue? Part of that very situation that you're talking about addresses the stigmatization of AIDS. Everybody has the "not in my own backyard" issue and the small town community that has its first AIDS case, that person's going to migrate for a lot of reasons. They're going to migrate to an urban area where they can be treated without the stigmatization. I think part of that comes back to the fact that it's time that someone besides the Surgeon General of the United States speak up strongly in the area of AIDS education. And until the country accepts the responsibility in the local community that they can provide a visiting nurse service and that the person with AIDS can reside in their home without stigmatization, we're always going to be faced with migration problem.

MR. DeVOS: Because ideally you'd reverse it. They would return home where they've had better care and loving care.

MR. BROWN: I think there could be some incentives to the local community hospitals and the local community health providers to make it cost effective for them to encourage the person with AIDS to remain in the community.

MR. DeVOS: I visited with the people at Henry Ford and they said, "Well, all the little hospitals say we don't know how to do." And Ford answered this "we don't know how to do it either and you're going to have to learn just like we did how to care for these people." But that's a tough problem and a tough educational problem, as you point out.

MR. BROWN: Telephones work. They can call and ask questions.

MR. DeVOS: Otherwise it just concentrates in certain areas of the country and the problem gets staggering.

CHAIRMAN WATKINS: And also it misleads a lot of Americans as to what's going on. They say, "Well, it's all happening in New York, why should we be in on it?" In San Francisco we were inundated with statements that many of these people migrate there because they have the most sensitive alternative care settings that can be made available. Well, we need the data on that.

From the existing files of information you have on the various hospitals or other settings, can tell us, who are the people that are coming from other sites, when do they come to you? Not that you want to solve that problem directly, but it's an indication of the national status of this epidemic and it doesn't allow people to say this is a New York or San Francisco or Miami problem.

If it is in fact because of stigmatization they are migrating to areas where there's more sensitivity to them both in getting quality health care and an accepting point of view, it seems to me that that kind of information will be very useful to air. And let's find out if there is a migration out of Texas, for example, to California, to the San Francisco area? If so, we ought to know that. Probably we have the data somewhere and if we can extract it, we can air this and use it as a wedge nationally to demonstrate that this is a national issue and not a local issue.

MR. LAWRENCE: You may, indeed, have some of that data available through the Centers for Disease Control because on the reporting forms for AIDS are the birthplaces of the individuals plus the names or listing of where the person has been diagnosed. So you may get some, at least baseline, evidence from that.

CHAIRMAN WATKINS: Can we task Mr. Anderman to do some homework in that area for the state of New York? It seems to me that it's to your advantage and we can certainly write your counterpart in the state of California. But coming from the health care financing people this seems to me would be a very important tool for us to have in our kit bag.

MR. BROWN: If I could raise one question to that. Since CDC has more money than any of us at this table and has more staff, couldn't they put a project -- personnel --

CHAIRMAN WATKINS: Does CDC have access to the information that--

MR. BROWN: They can qualify the birthplace and the diagnoses location and treatment facility on--

CHAIRMAN WATKINS: Well, Dr. Mason will be here testifying before us tomorrow, we'll hit him with that task and, Mr. Anderman, we'll let you off the hook. However, if you have information --

MR. ANDERMAN: We'll take a look, yes.

CHAIRMAN WATKINS: I think it's to your best interest in the state, it seems to me, to know this, who is migrating in and out relative to this disease. I think it gives you a lot more leverage in your discussion about this thing not being solely a New York issue. Go ahead, Rich, I'm sorry.

MR. DeVOS: No, that's fine. I'm all set. You're just doing great.

CHAIRMAN WATKINS: Dr. Conway-Welch?

DR. CONWAY-WELCH: Mr. Chairman, I'd like to make a comment and then ask two short questions. In the hearings that we've had before there have been some issues regarding financing and nursing that we've saved for the finance hearing. I just wanted to briefly summarize some of those that have been presented to the Commission for the record and then ask two questions.

There were several points that I think are important. One is that there needs to be some kind of a tuition and stipend loan program to nursing students with a forgiveness clause for those who work in medically underserved areas as defined with the expanded definition that includes community health centers, et cetera.

Another recommendation was that models of nursing care that utilize nurses in different job descriptions based on different levels of education should be explored in order to more efficiently use nurses based on their educational background.

Another recommendation was that direct reimbursement for nursing care from Medicaid/Medicare and private sources should be able to be received directly by professional nurses for that care.

Another recommendation was that recruitment monies for people interested in advanced levels of nursing care need to be identified but there also needs to be a focus on minority recruitment. If continuing demographic rates hold steady, something like one in three United States citizens will be a minority by the early 2000s. Asian, black and Hispanic. And if we don't have nurses from those groups able to be culturally and linguistically sensitive to patients, we're going to have an additional care deficit.

One of the other recommendations had to do with Medicare passthrough monies that are currently being used for graduate medical education alone. Even though regulations state that these funds should be available for graduate clinical education which includes more than physicians this needs to be clarified to ensure that nursing is clearly included.

We've heard some different ideas about the effectiveness of case management and one recommendation that has come to us has been for nurses to assume a greater rule in the area of case management. I wondered if Dr. Maraldo could expand on that briefly and then I'd also like to ask Mr. Anderman if he could give us a bit more of a snapshot of the RUGS model that might have some usefulness in terms of an AIDS population? You may have written information on that that might be appropriate. Dr. Maraldo?

DR. MARALDO: Surely. Given that the case management approach is preferable in treating a chronic illness and controlling costs, and given that the ala carte fee for service approach in treating AIDS patients would probably be financially untenable, then it becomes furthering to think of treating AIDS patients by combining the best possible combination of services in the best possible settings for the lowest cost. And in that sort of a mode, since nurse providers have been shown to deliver just as high quality of care for lower costs, it would seem that the primary care giver that would follow patients across settings post discharge from the acute care setting should be -- could be the nurse provider as case manager.

DR. CONWAY-WELCH: How would you pay that individual?

DR. MARALDO: That is --

DR. CONWAY-WELCH: That's where you usually get hung up.

DR. MARALDO: That individual should be reimbursed in private insurance packages by private and commercial insurers as well as under the Medicare program.

I think that the model that the VNA's currently use is -- the home health industry uses is a viable model. The problem from the nurse's perspective is that the nurse is primarily involved in carrying out the medical regime or the medical plan of care when, for chronic illness, which by and large you see out of the acute care setting, it's inappropriate; so that the nurse is in a position to provide that care, provide nursing care, independently. But I think it would be built on that model.

DR. CONWAY-WELCH: Thank you. Mr. Anderman?

MR. ANDERMAN: The quicker snapshot or a quick snapshot is RUGS basically defines for the long term care patient 16 different levels of care and the lowest level of care we call physical A,B and C. These are patients who are fairly ambulatory--

DR. CONWAY-WELCH: Now are they reimbursed differently? Are those levels --

MR. ANDERMAN: Yes. There are 16 different levels of reimbursement which are linked to the care needs of the patient. And what we did with the model that we developed is we looked at the AIDS patients and the levels of care that we define for the RUG categories which have to do with activities of daily living, dementia issues, a variety of other kinds of care needs of patients. And then we looked at the other issues that you've heard discussed, the pharmacy costs, infectious disease issues, education, the case management issues and we basically restructured the payment system for the RUGS program. And so as an AIDS patient comes into a long term care facility, that patient will get looked at just like a patient who we would try to categorize in RUGS and then the financing of it has been increased to reflect the levels of care needs for those patients to that. It roughly has worked out to be about $45 to $50 a day more for that patient over on top of the RUG patient.

Now, in the smaller facilities you've heard earlier mentioned, the ICS, there are some diseconomies of scale because of the size of the unit and the requirements, federal minimum requirements for Medicaid participation for a nurse and around the clock staffing, which cause some dis-economics. Because we want to get the programs operating in some of the smaller units, we think would be very good care providers as well as there's certainly a savings to get the patient into this setting from a hospital, we've bit the bullet on the diseconomies of scale and have recognized that in the payment.

DR. CONWAY-WELCH: The reason I'm asking the question is that Mr. DeVos raised the issue this morning about whether or not we haven't Band-Aided Medicaid and Medicare to death. And Mr. Yezzo, who is the Administrator at St. Clare's Hospital, of reinforced that but different models needs --

MR. ANDERMAN: Yes, I know Rich. Rich misspoke, I think. That this was not a Band-Aid. This was basically taking the patient --

DR. CONWAY-WELCH: No, no. What I'm hearing is that this is not a Band-Aid. This is a model that might take us beyond the Medicaid and Medicare Band-Aids that we're so desperately trying to put back together and to find some, alterative models.

I appreciate what you're suggesting and I think it would be useful for us to look at that. Is that collated in a --

MR. ANDERMAN: We have lots of information written up on RUGS. I'd be happy to send it to you and the additional things --

DR. CONWAY-WELCH: I think that would be helpful.

MR. ANDERMAN: -- that we've done in regards to the AIDS patients, we can give that to you.

DR. CONWAY-WELCH: Mr. Chairman, would that be acceptable?

CHAIRMAN WATKINS: Absolutely.

DR. CONWAY-WELCH: Thank you.

MR. RIGER: If I may, you raised the question earlier of direct reimbursement to nurses to care for AIDS patients. While I think in some instances it may be appropriate, in the larger prospective that may, indeed, have negative effect because of the complex mix of services, disciplines and the need for round the clock coverage in some cases, supervision of paraprofessionals and so on. One needs a coordinated system, one needs relief for the care givers. In very many of the cases the spectrum of care has moved down one notch further. Not only has it moved from the physician to the nurse, it has now moved to the paraprofessional where many of our patients require basically unskilled care, that is assistance with the activities of daily living, the feeding, dressing, tolieting activities which need to be supervised, of course, by a nurse but in the long run the focus of care has moved downward in the spectrum of the health care providers. And one needs a coordinated approach that involves all disciplines. It would be very difficult to envision a system that pays each one of, perhaps, ten providers as independent practitioners around the care of one patient.

DR. CONWAY-WELCH: I think that your point is well taken. I think you may have just made the case for nursing case management. I'm not suggesting that every individual provider bill separately, but that a certain level of nurse with certain skills may well be in a case management position where they are, in fact, coordinating the care. There would be some paraprofessionals who would be involved sometimes in the day-to-day management of the patient, but the nurse case manager is involved in coordinating that care.

I certainly am not interested in seeing a more fractured system than we already have, but I also think that the physician as the gatekeeper of reimbursement is a model that is not serving us well not only in this crises, but in other crises. There needs to be a way of moving toward more coordinated care with different stake holders involved in trying to be part of that care. Would you care to comment on that, Dr. Maraldo?

DR. MARALDO: I quite agree. Thank you.

DR. CONWAY-WELCH: But the point you raised is an important point because that's the first point that's raised in terms of identifying a problem with that suggestion. It's important to get information out as to what some of the underlying issues are regarding that.

DR. MARALDO: Dr. Conway-Welch, if I could reinforce something that I said earlier to Dr. Lee along these lines. The problem currently in not using the nurse in their appropriate role of patient coordinator and coordinator of the interdisciplinary team when dealing with chronic illness, not acute chronic illness, is that it's provided a very strong disincentive for nurses to come into the discipline. And I reiterate that I think it's a major, major factor as to why we're -- little girls don't want to grow up and be nurses anymore and little boys never did.

DR. CONWAY-WELCH: Little girls are becoming physicians.

DR. MARALDO: That's right.

DR. CONWAY-WELCH: Thank you.

CHAIRMAN WATKINS: Mrs. Gebbie?

MRS. GEBBIE: A request for some clarification and additional numbers, not something I think can be answered right here. I think it would helpful, Mr. Crane, if we could see from Kaiser some breakdown of how you put together a package of care and what it costs for a sample of a 100 patients with HIV or for an individual, how you fit in whoever it is you use to manage the care. I think you use nurses, at least somewhat, in that role as well as physicians somewhat, but maybe others. And I think it would be helpful to us to see that.

The other question I have. In my notes, I direct this to Mr. Anderman and Mr. Riger, but others of you may have done this. I get very nervous when I see the cost for hospital days compared with the cost for home care days because generally when I've asked the home care days only include the health care portion of the home care days, not the rent and the food and the other things that are not necessarily being provided by separate fees when the person is hospitalized. So could you double check any of you that gave us that kind of comparison, that you include actually what it would cost for equivalent maintenance of the patient, being able to eat and everything while they were getting that care so that we can look at the numbers a little more plainly?

MR. RIGER: Yes, I think your point is very well taken that we have to be sure we're comparing apples and apples here. But if you really look at the question, it is appropriate expenditures of dollars more than absolute dollars expended. If it costs $1,000 in the hospital per day for some cases and we can treat them at home even with a drug regimen and so on, for approximately $100 a day. So let's say you add $50 or $100 additional for the overhead cost of keeping a patient at home, it still compares very favorably with the $750 to $1,000 in a hospital. But we have to be careful when we quote this kind of data.

MRS. GEBBIE: I have no question about the more appropriateness of that care even if it were a dollar for dollar shift. In the case of many patients it is appropriate to be at home. My concern is if we start running out costs and give out the idea that you can maintain people at home for a number that's wrong because it doesn't include what it's going to take to feed them, we can end up with some very skewed numbers in our report. So I just am trying to be very accurate in what we pin down.

MR. RIGER: I would add one more thing to that, too. Often a hidden cost that never shows up in anybody's data is some of the unreimbursed care that's provided, not only by agencies and professional providers, but also by volunteers, by friends, relatives and so on. All of those have to be added into equation.

MRS. GEBBIE: If you can give us an equation that adds that in for the typical patient in your care, that would be very helpful.

MR. CRANE: Our Northern California Region has just completed a comprehensive study for the Office of Technology Assessment on the impact of AIDS in Northern California. In that report we did a sampling of costs and provide a breakdown of costs by type of service. And we'd be happy to provide that to the Commission.

MRS. GEBBIE: Thank you very much.

CHAIRMAN WATKINS: Well, let me ask it in another way, and maybe this should be to Mr. Anderman since you're in that direct business in the state. Are there legitimate cost benefit analyses which show the wisdom of up front investment so that we don't end up always being frightened by the initial investment and can see some amortization over time.

I have yet to find anyone who has really done this type of work well in a concerted way, that is not just anecdotal information.

It all sounds good -- we can avoid a prison slot and maybe close a prison as a matter of national self pride at some point in time as an objective because we have done all this preventive work that's so cost effective. Who does that analysis? Is it ever done except in a kind of a anecdotal way that doesn't seem to make the impact on the nation? If we want legislators to vote the kind of dollars we're talking about here today, we've got to demonstrate that four ounces of prevention is still worth a pound of cure. And I don't see that coming out of the cost analysts. Even your "AIDS in New York State," it's an excellent document, but what it doesn't show is amortization regimes on costly up front health care concepts.

I recognize we've got human beings and I recognize there are social benefits besides cost. Let's get the data where we can to really demonstrate that certain projects that we've been involved in are, in fact, cost effective.

Now we've had some impressive information coming out of San Francisco on real hard data that gives us a cost per HIV infection that is considerably less than the data I've seen come out of the East. Now how good is that? What kind of objective and analytic approach has been taken so it doesn't become a self-serving sort of a document? "Look how good we're doing with our program,therefore give us more dollars." It's got to be something much more objective than that. And it seems to me that the states that are heavily impacted here would be looking very hard with green eye shades at the kinds of programs that we can demonstrate to our state legislators that really make a lot of sense and that we -- yes, we have to make this $100 million up front investment, but we will track it, know how to track it and can demonstrate amortization. We'll be back to you in two years and then four years to demonstrate our facts. What I've seen so far doesn't look like it has the rigor of the kinds of things that we would have to do in Defense to ever get a program going off the ground.

And I think, too, we've waited too long in the human resource side to try to find the mechanism to convince ourselves that this makes a lot of sense. Prevention is a good program not only from the social side or the social benefits, but just as importantly from the cost benefit side.

MR. ANDERMAN: Well, I think, Admiral, I'll answer your question in two ways. I think, first, we've just taken a big breath and finally begun to cost the various different modalities of service. We've just finished that in the last two months with the long term care component and the home care component. And I think you're right. In the book that I've given to the Commission members, we did do an estimate, for example, time loss and the amount in the state and it's a staggering number like $1.7 billion of the economy of New York state.

We're going to be starting what you're asking for. But we haven't done the kinds of cost benefit analysis that we expect to do. We're starting to do that with some of our public health activity. We're starting to look at some of the economics of trying to provide, especially in the obstetrical-pediatrics area and we made the decision to go ahead and pay for testing and counseling for any mother who is involved in any of our public health programs in prenatal care because it clearly is a cost benefit there. And we convinced the legislature to fund that, which they did do this year.

So I can answer your question in two ways. We've got, I think, the cost side now costed. And I think we're beginning to turn our attention to the benefit question. And --

CHAIRMAN WATKINS: What would you recommend that we do as a Commission in forwarding our report along these lines to bring the proper people together, particularly in the heavily effected states, to sit down and to look more critically, at those elements that can be costed out properly. We need to identify cost offsets that would otherwise have to be there for health care that we could have avoided. Those things that we don't think are that cost effective, we shouldn't be selling on a cost effective basis, we ought to be selling on some other basis if, in fact, they're still valid.

It seems to me it's time to start moving along those lines, otherwise because we keep getting hit with who is going to pay for this. We've even been accused of throwing dollars at the problem. I don't think we are throwing dollars. I think we've been very responsible that way to try to walk on the line and as narrowly as we can to define it around the HIV. I don't get the hard ringing answers that I'd like to get out of cost benefit analysis. We're not going to sell new money for AIDS to people who are facing tremendous deficits on that basis. We might be able to do it with people like American industry who know that their own investment is saving them dollars where they have used good management procedures, such as Mr. DeVos uses in Amway. They can see the importance that work force keep its moral up, keep people in the workplace, keep their health insurance and keep working the problems. And, obviously, they're making a major contribution to society.

We ought to start looking at cost-effective programs now because it may take several years to get them in place, and it seems to me we have a tremendous set of health care problems were AIDS never to have arrived that are almost every bit as serious. AIDS is only exposing all of the flaws in the system.

MR. ANDERMAN: I would recommend to you that through various different organizations at the federal levels that dollars become available or additional dollars become available to fund these types of projects. Maybe what you're asking is the health service research activity to look at the cost benefits of programs to treat this particular type of illness.

CHAIRMAN WATKINS: If you were interested in doing that and you were a member of the Commission, how would you draft up that tasking so that it read right, and people in your business looking at it would say, "Yes, that's a smart thing to do, it's about time we did it"? If you had to write up a request for proposal, for example. Can you submit something like that for the record? Here's an opportunity for us to make a proposal that might assist you in your own work at the federal level, state level and even local level if we can stage it right.

MR. ANDERMAN: Well, I think you've --

CHAIRMAN WATKINS: I wouldn't want you to try and answer today. I'm just asking you if you think it's a tasking that's worthy of giving with some help on the way to effect it.

MR. ANDERMAN: I'd be happy to give it some thought.

CHAIRMAN WATKINS: Would you?

MR. ANDERMAN: Yes.

CHAIRMAN WATKINS: And would you either give us a call or give me a me or write me a note saying, "Yes, this is the way I would task it up and this makes some sense."

Any of the others that would like to join in on it, I think it would be useful for us to have it from Mr. Crane's point of view, for example, coming in from your angle because I think you should be a joint participant in this. I see the variety of funding entities coming together and being satisfied that we're incorporating the mix of funding sources properly in this analysis.

MR. CRANE: I would agree. One piece of information which the Commission may have already been exposed to is within the National Center for Health Services Research. They are sponsoring a project to design a long term study of the cost of AIDS care in different settings. I'm not exactly sure of its status, but there are people in academic settings that are working on protocols, as I understand your question, that would address it almost directly.

CHAIRMAN WATKINS: Will this be ready for us in fiscal '99 or is this something that's being done at the right level of urgency for this emergent disease?

MR. CRANE: Well, that is a good question.

CHAIRMAN WATKINS: Do you have access to that particular piece of information?

MR. CRANE: I do not, but I know some of the people who are involved in it.

CHAIRMAN WATKINS: Well, any of you that feel like you could make a contribution to us on it, we'd appreciate it and I would like to know specifically from Mr. Anderman if you think this has merit and if you think you could phrase something for us that would make some sense. We'll be listening to have more witnesses tomorrow on the same subject, so it's not the sole source but an independent source is sometimes useful to us to us.

And we thank you for coming before the Commission today. It's been helpful to us and we'll possibly want to have continuing dialogue with you between now and the time we put our report together. Thanks very much.

(Whereupon, a recess.)

CHAIRMAN WATKINS: The last of our panels this afternoon on assessment of total cost and national economic impact. Dr. Jane Sisk, Health Program, Office of Technology Assessment, Congress. Dr. Anthony Pascal, Senior Economist, The Rand Corporation, who has to leave at 5:00 so let's watch our questioning and make sure that we get all the questions focused on Dr. Pascal we need to him by that time. We have returning to us John Thompson, Yale University School of Medicine. We're glad to have you back with us, Mr. Thompson; and J. Patrick Rooney, Chief Executive Officer, Golden Rule Insurance Company.

We'd like to commence now with testimony from Dr. Sisk.

DR. SISK: Good afternoon. I'm Jane Sisk from the Office of Technology Assessment. And I'll be drawing my remarks today primarily from an OTA study in which we reviewed several studies on the cost of AIDS.

With the survival and treatment patterns documented in studies through mid 1987, AIDS lifetime hospital costs have most likely been under $100,000 and estimates of annual treatment costs for patients alive at any time during the year have been under about $40,000.

These figures put the costs of treating AID in about the same category as the cost of treating some other serious illnesses, such as end-stage renal disease for patients undergoing dialysis. These figures are clearly incomplete, though. They count almost exclusively in-patient hospital expenses, sometimes ambulatory drugs and ambulatory physician services, and almost never nursing home and home care costs. Studies have not looked at the costs of HIV infection as opposed to outright AIDS and have almost never have included ARC. None has examined the lost of pediatric AIDS cases.

It's not clear that all the costs associated with AIDS treatment have been counted in these studies. One reason is that the studies have been done retrospectively from whatever records were available, and that's mainly been in-patient records. That's not the fault of the researchers who were doing the work. They did a commendable job with what they had available. It's just that data on costs of particularly illnesses across different parts of the health care system are simply not compiled routinely in this country.

The results from the studies I've mentioned also may not be generalizable. For the most part, they pertained to a small sample of hospitals, and a small number of patients and mostly come from California and New York.

Another factor to consider in looking at these studies is that they were done primarily from 1984 through 1986. The way that AIDS care is managed has changed in ways important since that time. AZT, for example, is more generally used now than it was then and that may add costs in the ambulatory area, but it may subtract them from the in-patient area. On balance we don't know what the result of changes in those kinds of therapies as well as other changes have had on total costs.

We also lack definitive information about who is paying for AIDS care. Medicare has paid one to three percent, which is much less than Medicare pays for general medical care because AIDS patients have been young and have not lived long enough to become eligible for Medicare as disabled people.

HCFA has estimated that Medicaid has paid for about 23 percent of costs for about 40 percent of patients. That's much higher than for other medical care, but the estimates from particular studies vary widely as to what Medicaid actually pays for. Tony Pascal may speak to that later.

There's not much information, certainly not much systematic information, on what private insurers are paying and to what extent people with AIDS have no health insurance coverage and must rely on their own assets or on government programs.

The most comprehensive and rigorous study of national costs was conducted by Anne Scitovsky and Dorothy Rice, who estimated the total costs associated with AIDS, including direct medical costs of caring for patients and indirect costs associated with the illness (measured mainly in terms of working loss) those total costs were estimated to be $8.7 billion in 1986 and were predicted to reach $66.5 billion in 1991. Indirect costs in those calculations were about 80 percent of the total, mainly because of premature mortality.

In 1986 an estimated $1.1 billion was spent on treating AIDS patients. About half of that amount, about half a billion dollars, was spent on preventive activities, according to the estimates of Scitovsky and Rice. About half of prevention expenditures went to screening the blood supply, 43 percent went to research, and only six percent went to education.

These cost estimates, it goes without saying, are also incomplete for the same reasons I gave before. It's also unlikely that they took into account work regarding AIDS that's going on in clinics for sexually transmitted diseases, for example. And they suffer from what all cost estimates do, and probably will in this field -- the fact that treatment is evolving and the costs of care are changing over time.

What this paints is a picture that we need the following cost data to improve public and private decision making. We need comprehensive information on the total costs of care in all settings and from all providers. Those data should be collected respectively and include the costs of HIV infection, not just AIDS, and the costs of pediatric cases, not just adult ones. I know of only one such study that's underway for a small number of patients in California, and Ann Scitovsky is involved in it.

We also need costs by payer, so we know what the needs are and who's paying for what now. The information so far, including from Dennis Andrulis' study through the National Association of Public Hospitals, suggests not surprisingly that compared with private hospitals, public ones are caring for many more Medicaid patients and patients with no insurance. Especially in the south, where Medicaid rates are lower and charity care higher, revenues seem to be falling far below the reported costs of caring for AIDS in-patients.

Such cost information would help public and private decision makers determine the most cost-effective methods of delivering care and the mix of hospital, home, and community services that are most appropriate, for example. Such cost information would also let policy makers predict the personnel and facilities needed to care for people likely to become ill in coming years and plan how to marshall those resources. And such cost information would inform policy discussions about how to share HIV costs equitably among payers.

What makes HIV infection and AIDS a special case is the increasing prevalence of the disease and the age groups effected. Besides the needs for data just outline, AIDS is raising once again long-standing issues of how to pay for the catastrophic costs of illness and how to allocate resources between prevention and treatment.

It's clear that the costs associated with HIV infection will be paid by different payers: private insurers; federal, state, and local governments; and patients, their families, and friends. How the costs will be distributed among these payers depends a great deal on public policy. Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Sisk. Dr. Pascal?

DR. PASCAL: Thank you, Admiral Watkins, for inviting me here today and the other Commission members. What I would like to speak about are some conclusions from a report that we prepared at RAND for the Health Care Financing Administration on the cost of AIDS under Medicaid which required us to make some national projections of AIDS cost using studies already extant. We did no original data collection for that study. And then go on to talk to you about some current studies underway that perhaps will begin to answer some of the questions that were posed on the earlier panel.

I'd like to put my sort of central table up with estimates that I derived for that report. These are revised a bit from the report because of changing information about how the costs were coming out. And these are estimates of cumulative events over the period 1987 to the early '90s, '91, '92. And I want to talk about the intermediate forecast because I think it's the most reasonable one.

The nation will have experienced by that time something like 400,000 cases of AIDS and will have been through that many experiences with the illness. But about 30 percent by that time of the patients with AIDS -- and this is not adjusted for the new definition that came out after our report was published, although I would think the 400,000 would be fairly close because the heterosexual spread has been somewhat less than we were anticipating but, on the other hand, the new definition brings more people into the case load.

The percent on Medicaid, we think by then, will be something like 30 percent of all cases. The costs will be down to $70,000 lifetime or lower. And that Medicaid will reimburse at about 60 percent of the charge level as they've been doing. So that gives us a national costs for that time period of something like $28 billion cumulative and Medicaid costs of something like $6 billion. And this will account for a fairly small fraction of total national health care expenditures, maybe two percent or so. A somewhat larger fraction of total Medicaid expenditures.

I think what would be interesting to talk about is what would make these figures go up, and what would make them go down over the estimates that we have made here. If we can first concentrate on the national figures, I would say the following would do so. If the conversion rates from HIV positive status to symptomatic AIDS are higher than has been anticipated, of course the case load will grow and so will these costs.

I think if there are more drugs that work as AZT works -- not that I am against it by any means, I think it does help patients -- but, that I think on net is going to raise costs because of the treatment of side-effects, because of the cost of the medication itself, and because of the longer survival. When you bring them all together, I think the tendency for these kinds of therapeutic drugs is to raise costs to some extent.

I think if the case management approach developed in San Francisco does not spread as rapidly as it has been doing and bringing costs down to the $30,000 to $40,000 per year level, then I think the costs will be higher than I've been talking about. But, we also know that the San Francisco model is heavily dependent on the use of volunteers and volunteer networks. If we can't expect those to develop in other parts of the country, costs may be higher than anticipated.

Finally, if new viral strains come along and contaminate the blood supply again, then our case load estimates will go up.

A few points about what would change the balance between the share that Medicaid pays, the public side, and the private side. Longer survival tends to mean more patients on Medicaid. They run out of private health insurance. They even -- some people on AZT are living beyond the COBRA protection that they get when their large group health plan ends with the end of the job and then you get 18 months of a guaranteed continuation policy. People who live beyond that 18 month period usually go on to Medicaid for the final days.

There's talk about reducing the Medicare waiting period from the 24 months. Clearly, if the Medicare waiting period gets reduced, people will prefer Medicare to Medicaid. And so, that will probably raise public costs generally because Medicare reimbursement rates tend to be a bit higher. But, it will reduce the Medicaid side.

If the heterosexuals who become infected from tertiary infections have the same kinds of pathologies and the same kinds of socioeconomic status that the IV drug users have, then I think we'll see higher public sector costs again, because these will be more likely indigent people who will not have private health insurance.

If insurance companies begin to screen more intensively -- they're not doing this very much at all now for large group policies, although people have alleged that the insurance companies are considering screening in large group policies -- again, the public sector end is going to go up.

If insurance companies are able to institute caps for AIDS treatment in the way they do, say, for psychiatric or maternity treatments, again, people will run out of benefits on the private side and go on to the public side. Prior condition exclusions, if they are more heavily used, say, in large group plans, will have a similar kind of effect.

Finally, I think if there are plans afoot to extend COBRA beyond the 18 months -- many states have what are called "mini-COBRAs," which gives COBRA protection to people in small group plans and even guarantees continuation of individual policies at fixed rates -- again, if none of these things occur, again, the public side is going to rise. I think all of this suggests the criticality of more information on who's paying what for AIDS treatment and who ought to be paying what. I think the Commission has a real responsibility to come up with a wise and effective and compassionate plan for sharing this burden.

I just want to mention a couple of studies we're doing now that emphasize to me how important this is. We are working with a panel of 40 AIDS patients in Los Angeles, along with Anne Scitovsky, whose collecting provider cost aid, and we're collecting "How did you pay for the cost of your disease?" data directly from the patient. "What did you do? How does your insurance policy work? How much was your co-payment and your deductible? How did you loose the policy and have to go on Medicaid? To what extent has your family helped with expenses? To what extent have your own assets been devoted to this?

From very early indications, we are finding a substantial amount of self-pay amongst these patients. That is, payments that come directly out of pocket from the patients themselves or their families. We have proposals in to launch similar panels in New York City, Chicago, Houston, and the District of Columbia, and we're hoping that those will be approved so that we can begin collecting this information on "How did you pay for the cost of your disease?" How was AIDS care financed on a national basis?

We've also been talking about trying to use, in collaboration with the health insurers in the United States, claims data that preserves confidentiality and individual company security to begin to get a feeling for how treatment has evolved in the private sector, how it's changed over time, and how it differs on a regional basis from one city to the next, and finally how people loose their insurance before death and what conditions might apply.

I just want to end by saying that the early reports of the Commission have been extremely commendable, the preliminary interim reports, and I hope that the good work continues and I hope the people in the federal government who've been supporting RAND in doing these studies, and the other groups that have been engaged, will be encouraged to continue doing that, because I think these are critical questions for the nation. Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Pascal. Mr. Thompson?

MR. THOMPSON: Thank you, Admiral. It's nice to be back and to see that you have progressed as far as you have.

Dr. Pascal has been talking about societal costs, which are important, but we must not forget to track treatment costs. Treatment costs are analogous to production costs, in that they reflect the volume and price of all resources expended in the care of the patient, the cost of the actual treatment process itself.

We need to develop monitoring systems for the care and financing of treatment of persons with AIDS by merging clinical and epidemiologic with claims and cost data into a planning and management information system to permit government use to project future strategies in the treatment of AIDS:

1) to identify the need for new programs;

2) to assist in the fashioning of new waivers that would be necessary to finance alternative programs;

3) to inform legislatures of the cost implications of the treatment of AIDS patients, particularly as it refers to the Medicaid program;

4) to inform official and other involved agencies on the volume of institutional services given to persons with AIDS and the effect of that volume on the spectrum of health services offered by the licensed institutions;

5) to assist in the utilization review function;

6) through exploration of alternative delivery sites, to encourage other community agencies including hospitals to respond to some of the promising new approaches in the treatment of AIDS patients;

7) to add to the general knowledge of the economic implications of the treatment of persons with AIDS.

I'd like to present today some examples of the kind of information needed to support the planning of treatment programs drawn from two preliminary studies from Connecticut.

May I have the first slide, please?

The Panel has these slides, and so you don't have to crane your necks. The first three pages are a cooperative study done with the Department of Income Maintenance, which runs our Medicaid program in Connecticut. And although people have been critical of Medicaid, it happens to be one of the single places where you can get charges for care for inpatients, outpatients, physicians and drugs, all in one record.

This is just a preliminary study of the study we're going to, we hope, complete this summer. This involved only 74 adults and 12 children. You can see that the total charges for the time covered of 14 months was $35,000. Inpatient costs were 76 percent of that number. Outpatient charges are relatively low at 8.6 percent. Physician charges are 9.1 percent and drug charges are 4.7 percent.

MR. THOMPSON: When you look at the children's data, you will see that the mean charge is a little higher. This happened to be very heavily distorted by an outlier case. But the percent of hospital expenses or charges are still 90.1, higher than for adults. Lower in outpatient and physician charges and drug charges.

The hospitals and physicians were reimbursed at about the rate very close to the one that Dr. Pascal mentioned. Approximately 56 percent of charges was the actual reimbursement rate.

The next chart just shows you the real problems of the distribution of these cases. As you can see, it is quite a wide variation. The important thing is here that good utilization review covering relatively few long-term patients could really cut the average cost down. This is what we're talking about and you were talking about, managed care. This is what managed care would do. It would cut the cost down for adults and also for children. Of course, there's only 12 children there. That's the target for managed care.

Now, the next chart attempts to obtain what we call a charge profile. These are the average of 24 admissions where the data is broken down by hospital components. This was in one single hospital. It averaged $13,800. Fifty one percent of the charges were for room and board.

The influence of AZT is beginning to show. Fifteen percent of the charges were for pharmaceuticals. Laboratory charges were the next costly type of services. There are two important findings in the chart. The first is a relative unimportance of the high tech aspects of hospital costs such as operating rooms, CT scans, cardiovascular laboratories, et cetera. This is evidence that many of these individuals could have been treated in alternative sites.

The second finding is the importance of nursing care. Fifty percent room and board costs are for nursing. Nurses administer the medications and monitor the intravenous infusions and the oxygen. These patients are in the hospital primarily for nursing care.

CHAIRMAN WATKINS: Thank you, Mr. Thompson. Mr. Rooney?

MR. ROONEY: Thank you. My name is J. Patrick Rooney. I'm Chairman of the Board of Golden Rule Insurance Company. My subject deals with coverage in connection with individual health insurance. That is the kind of insurance that a person would apply for individually and provide to the insurance company evidence of good health.

Today, Golden Rule is the largest writer of individual major medical insurance in the country. There are some 75,000 independent agents and brokers who write Golden Rule Insurance. Also, several of the nation's largest companies have contracted with Golden Rule to have our individual major medical insurance available through their career agents.

Golden Rule has done some HIV testing. In fact, in Washington, D.C. when the city council passed a law that forbad HIV testing, Golden Rule withdrew from the market along with other insurance companies.

Today however, because of the agony over the matter of testing, Golden Rule has come up with a positive alternative, an innovative policy that permits people to get individual health insurance without doing HIV testing. The new policy stems from our recognition that many reasonable people object to mandatory testing.

For my own part, I've been a long-time member of the Civil Liberties Union and I'm on the Board of the Indiana Civil Liberties Union and I have at least some understanding of the concern about mandatory HIV testing.

Another factor that influenced our decision to come up with a new policy was an article that appeared in THE WALL STREET JOURNAL1 last year. I'll quote one paragraph out of that article. THE WALL STREET JOURNAL article said, "The number of Americans without health insurance has risen to 37 million from

29 million people in 1979 and breakthroughs in genetic testing may soon make it possible for insurance companies to deny health insurance coverage to additional Americans deemed susceptible to serious diseases, much as many carriers of the AIDS virus are denied insurance today."

Well, we think something should be done about the public relations problem for the health insurance industry. So, Golden Rule has come up with an innovative policy that does three things. One, we would not require HIV blood testing for applicants. Two, however, we would not cover AIDS during the first 12 months that the policy is in force. Third, we would provide full coverage for AIDS treatment if the condition commences after the policy has been enforced 12 months.

Incidently, another aspect of this policy is we are also using unisex rates. The reason for doing so is we might as well get rid of all the social controversy we can all at one time. So, since that's an item of controversy, we figured we'd take care of it at the same time.

This policy provides a million dollar major medical coverage and does include coverage for home health care, nursing home care and hospice care. Historically, Golden Rule has been a low priced provider in the marketplace and that will also be true of the new policy. One of the things we have provided to the Commission is a dossier that includes the rates on the new policy.

Next issue is, is Golden Rule's position irrational? We believe that it is a rational response to the data that we have on the incidence of HIV claims as they affect our business in the individual major medical field. We believe it would be better for us not to spend policyholder money, and you know anything that the insurance company does, eventually the policy holders pay for. We believe it would be better not to spend our policy holders money on unnecessary tests if it would be necessary that the individual carry the insurance for a reasonable period of time before they could present a claim for AIDS. Therefore, we came up with the proposition that it would not cover AIDS until the policy had been in force one year.

Next, I want to say that I do not think it is our role to provide welfare payments to the testing industry. Every AIDS case we cover is a case that the taxpayer will not have to pay for.

We've introduced this policy this year. At the present time, six states have approved the policy for issuance in their states. One of the things, however, we have encountered is that a number of states object and will not approve it because it does contain a one year restriction, that is a one year waiting period. We will not cover AIDS during the first 12 months. People have to carry the policy for 12 months before we'll cover AIDS and some states object to that.

The answer that those states offer to us is you can test. Well, of course, we can test, and we are testing where it is necessary. But, every time we test and we decline people for insurance, we are not going to pay for their medical care and the taxpayers are going to. It seems to us that in the best interest of the taxpayers, it would be better to permit an alternative to mandatory testing. One of the things that this Commission can do is to advocate, if you wish, alternatives to mandatory testing.

I think that summarizes my statement. I'll be glad to answer questions.

CHAIRMAN WATKINS: Thank you, Mr. Rooney. We'll open the questioning from Dr. SerVaas.

DR. SerVAAS: My question is to Mr. Rooney. As I understand it, if the insurance applicant is positive for the AIDS antibody and knows he is, he can come to your insurance company and he or she can. If he gets sick any time during that year, you don't pay for it. But, if he gets sick after his first anniversary, you pay for all of his health care.

MR. ROONEY: That's right.

DR. SerVAAS: What I don't understand is why the states are saying you can't do this. In six states, you've done it?

MR. ROONEY: That's right.

DR. SerVAAS: It's working and they're coming to you and you're selling this insurance in the six states where you're operating?

MR. ROONEY: Oh, we are licensed in 49 states.

DR. SerVAAS: But, there are only six states -- did I understand you right -- there are only six states where you are now operating with this policy?

MR. ROONEY: Where this policy is now approved for issuance. Now, there is an aside. I need to give you another piece of information. It has not been submitted in every state, because many states require that you first have to have the approval of your home state. Our home state is the State of Illinois. That's where we come from, and Golden Rule is an Illinois domestic company. The State of Illinois has not acted either affirmatively or negatively.

So, until Illinois does act, there are maybe 20 states that we will not submit the policy to. But, all the other states that we have submitted it to, six have approved and probably about twice that many have positively disapproved on the basis that the policy may not contain any restriction on AIDS.

The only thing that the state would allow is for the company to test. Of course, the fact is if we test and we find this person has positive antibodies, we will turn that person down for insurance. Those states seem to think it would be better for us to test and turn those people down than to have a one year waiting period which we're proposing.

DR. SerVAAS: Well, they mostly don't get sick the first year anyway.

MR. ROONEY: That's right.

DR. SerVAAS: Most AIDS persons aren't going to be getting sick the first year they're infected, most aren't. So, I don't know why these states wouldn't think you're doing a real service to humanity.

MR. ROONEY: Dr. SerVaas, I don't know either, except of course -- so help me, I don't understand why.

You might possibly look at what happened in Washington, D.C. The law here forbade testing, and it also contained a provision that said, "No health insurance policy shall contain any exclusion, reduction, or limitation." It may be that what has happened is that as other states have said, "Well, you can test and you can turn people down for insurance," they have still kept this provision that says, "You can't have any restriction."

There's no doubt that what we're proposing does involve a restriction for 12 months. For 12 months, we will not cover AIDS. We'll only cover AIDS if it first commences, or the actual full onset of the AIDS happens after the first 12 months.

DR. SerVAAS: Well, what are you exactly asking? How can we help you? How can the Commission in our report to the President help you get the option?

MR. ROONEY: The Commission is very influential, and is concerned with the national concern about AIDS. The Commission can use its moral suasion to influence the states to permit alternatives to testing.

Now, the insurance companies are not going to put their neck in a noose. No company is going to wish to go broke over this matter. Certainly, we are not going to. But, the way we can do without testing is we can do with out it with some limitation, some 12 months limitation. After the 12 months, the people will have full coverage, not a dollar limitation. They would have the full million dollars coverage, but they wouldn't have it until they carried the insurance for 12 months.

MRS. GEBBIE: May I ask for clarification, because I think I heard you say two different things and I just want to make sure I understand. When I first heard you describe your coverage, I thought you said you would cover anything AIDS-related after the first 12 months. Now, I heard you say you will cover AIDS-related care if the AIDS itself commences after the first 12 months.

MR. ROONEY: That's correct. If I said otherwise, I misspoke.

MRS. GEBBIE: Okay.

MR. ROONEY: It would be that if it's first manifested --

MRS. GEBBIE: Twelve months after enrollment in the policy?

MR. ROONEY: That's right. Now, manifestation is not HIV-positive. It's coming down with a full-blown AIDS or ARC.

MRS. GEBBIE: Or any other symptoms? What if the person was symptomatic, but not fitting the classic AIDS definition in the first 12 months?

MR. ROONEY: We are attempting to live with the definition. Our intent, at least, as the policy is drafted is to use the definition that is accepted by the Center for Disease Control.

MRS. GEBBIE: Okay.

DR. CONWAY-WELCH: And which definition is that? How do you define that?

MRS. GEBBIE: That's defined by several opportunistic infections.

DR. CONWAY-WELCH: Right.

MRS. GEBBIE: But you are very clear that if that definition were applied to the person prior to the 12th month, then there would be no coverage at all?

MR. ROONEY: That's right. Absolutely.

MRS. GEBBIE: Okay. Thank you.

DR. CONWAY-WELCH: But does that also cover some of the manifestations of ARC as well as the opportunistic infections of AIDS?

MR. ROONEY: Yes, that's right, AIDS and ARC.

MRS. GEBBIE: ARC is not a definable condition by CDC.

DR. CONWAY-WELCH: I understand that but several of the symptoms of ARC are included in there --

MRS. GEBBIE: They're symptoms of AIDS.

DR. CONWAY-WELCH: -- as symptoms of AIDS. That's what I was trying to get at. At what point do you deem something?

MRS. GEBBIE: Oh, it's very clear in that definition.

DR. SerVAAS: What about AIDS dementia complex. Do you count that?

MR. ROONEY: If the manifestation occurs within the first 12 months and the doctors define this to be AIDS, then it isn't covered.

DR. SerVAAS: But his policy isn't canceled, you just don't pay any of this health care that --

MR. ROONEY: That's right. Thank you. That's an important point that I failed to mention. The policy, of course, covers anything else. If the person has an automobile accident or has a heart attack or cancer or whatever else you can imagine, the limitation only applies to the matter of AIDS and ARC.

DR. SerVAAS: But if he comes down with AIDS the first year, then the second year you do pay his AIDS premiums? Not premiums, you pay for his AIDS costs, his hospital costs?

MR. ROONEY: Yes. If it is manifested after the first 12 months, if the condition has its onset within the first 12 months, then sorry, no benefits. But if the person pays in -- you know, like the rest of us pay in for heart trouble. We don't know that we have heart trouble, but we buy our insurance when we're in good health so we'll have it when we're sick. Most of us have to buy it well ahead of time because we don't know when we're going to get sick. The unique phenomenon with AIDS is the person may go and get confidential testing and know that I am HIV positive and then go buy the insurance and have the first claim next month. Well, we're not running a charitable organization. We're trying to collect enough revenue to pay the claims. So, we're saying, "You've got to pay in for 12 months before you're going to have to have coverage for AIDS.

I didn't mean to advocate too strongly, I just wanted to be clear.

DR. SerVAAS: How many policies would you think you've sold, Mr. Rooney?

MR. ROONEY: Well, we counted up. From 1984 through now, through the first three months, we have written insurance on 1,200,000 new applicants. Of that, probably half of that business has been written in the last 18 months. So, let's say we're writing insurance on 600,000 people every 18 months.

DR. SerVAAS: But on this AIDS insurance policy that doesn't require testing.

MR. ROONEY: Oh, the new policy is we do not yet have it on the market. This is merely a technical problem. To be efficient, we need to have more jurisdictions. Now, we know we'll get more. I tell you six have approved it. We believe maybe a dozen, maybe 20. So, of the six states that have approved it, we probably will not actually offer this policy on the market until we have a dozen for technical efficiency, data processing reasons. The policy therefore will probably be offered on the market July or August. Have I answered you?

CHAIRMAN WATKINS: So there'd be no opposition from your company's point of view, for example, for a person to know they're HIV positive, asymptomatic, have that made aware publicly? You would certainly sign them up for your particular policy?

MR. ROONEY: Assuming he can get through the first year without any AIDS or ARC.

CHAIRMAN WATKINS: Let's say that an individual knows that they're HIV positive, has been tested and they're asymptomatic. Let's say they're in the first couple of years of the infection. They feel healthy, they look healthy, they're normal people from a health standpoint. Yet you are aware that they're HIV positive because you've been told that, and asymptomatic at this point. So, they don't come down with ARC or AIDS for two years. So, they qualify, even with your knowledge that they're HIV positive from the very outset, for your policy. Is that correct?

MR. ROONEY: Not necessarily, no. If we were told that the individual were HIV positive. Now that, I want to add, does not seem to speak to the reality. We are not told. We're not told that the person is HIV positive. We believe the only way we're going to learn if the person is HIV positive is to test. But if the person would volunteer on the application, "I am HIV positive," I don't know what we would do. All I can tell you is we don't face that issue because, in fact, we're not told.

CHAIRMAN WATKINS: Yes, but what if you ask? Will that mean the person will be rejected?

MR. ROONEY: Probably so, sure. This is all hypothetical.

CHAIRMAN WATKINS: Then I don't understand what you're offering more than anybody else is offering. It seems to me that the encouragement would be for those who are HIV positive to come forward and take advantage because you're basing everything on whether you're told or not. Supposing you find out the day after you sign the contract with them that they withheld information yesterday that they were HIV positive, therefore what would you do?

MR. ROONEY: Well, all of this is hypothetical.

CHAIRMAN WATKINS: It's very real because people are looking for alternative insurance options and you're one to provide that option. It seems to me you've done it. It's all written on the base of whether or not you get information that he or she is HIV positive, asymptomatic. That's the whole issue we're facing on discrimination and all the other -- whether or not they keep their job and so forth. We understand that insurance companies have exchanges between them that can provide certain information that leaks out from a variety of sources. It sounded very good at the outset and I'm beginning to question whether or not it really gets into the area of encouraging people to come forward who can continue to survive in this life with some expectations. If it leans on whether information leaks out that a person is HIV positive or not within the year, then I don't see what it does.

MR. ROONEY: The insurance company -- you said insurance companies exchange information. I presume you're referring to the MIB files. We do not do MIB searches on health insurance ever. It's just not economically worthwhile to do. But when we ask a person on the application if the person is in good health and the person said, "Well, I am HIV positive," you're posing a question that I don't know what we would do with. We do know that people don't tell us that and that it is readily available for people to get HIV tests and know themselves whether they're positive. But they do not volunteer it to us. Now, the issue is whether we are wiling to write health insurance without HIV testing and we're proposing we are.

DR. CONWAY-WELCH: May I ask a question?

CHAIRMAN WATKINS: Dr. SerVaas, are you finished?

DR. CONWAY-WELCH: No, I meant relative to this.

CHAIRMAN WATKINS: Okay.

DR. CONWAY-WELCH: Let me take another cut at this. If someone came to you and they knew they were HIV positive and you asked them if they were healthy and they said yes. They did not identify that they knew that they were HIV positive and then they became sick two years after their policy went into effect and you could document by virtue of a chart review or a mechanism that this individual knew that he was HIV positive when he signed up and did not volunteer that information, would you cover his illness, his HIV illness?

MR. ROONEY: If the person buys our insurance, regardless of what the ailment is, and lies to us on the application and there is a time limitation on how the insurance company can rescind or revoke the policy because the person lied, there is no dispensation from lying for anybody, regardless of the ailment.

DR. CONWAY-WELCH: So, if somebody is HIV positive and knows that and comes to you and when you ask them if they're healthy they say yes and they don't volunteer that information. Then they come down with an HIV related illness 18 months or two years into the policy, at that point by virtue of chart review or of prior knowledge in some way, would you deny that policy?

Let me take that a step further. Would you by virtue of the fact that we assume a certain time lag of HIV positivity before they move into ARC or AIDS, if that happened within 14 or 18 months, would your assumption be that they had lied to you? Am I making myself clear?

MR. ROONEY: You said is there an assumption that they've lied to us? The answer is no. For the most part, the people that are HIV positive, that knowledge exists between them and whatever testing laboratory that they were able to get to do it confidentially and that's readily available. If the person came down with AIDS at the end of 12 months and one week, our belief is we don't know when the person contracted it. We don't know whether the person knew. That information is not available.

DR. CONWAY-WELCH: Thank you.

DR. SerVAAS: I guess I would still have a question about what do you ask, Pat Rooney, on your application when you're selling this policy? Do you need to know if somebody has Huntington's chorea or diabetes or some other chronic disease that --

MR. ROONEY: Yes. We have a list of questions, a considerable list of questions. Of course, with the typical disease -- example, you or I applied and we said, "No, we've never had a heart condition." But if we have had a heart condition, there are probably medical records that will make it available that we've lied. That tends not to be true with AIDS, unless the person was under treatment for AIDS.

Now, we get a few people that -- some of our AIDS claims, we are able to demonstrate that the person was under prior treatment for AIDS. Of course they're in the same boat that the person with the heart condition is. That's fine if they can get away with it, but lots of times they don't get away with it, nor would you and I with the heart condition.

The thing we are offering that is unique is the offer to write the health insurance without the blood testing that would discern information that wouldn't otherwise be available to us.

DR. SerVAAS: Do you know if you just ask them outright on your form when they apply? Do you ask, "Have you been tested?"

MR. ROONEY: No, we don't.

DR. SerVAAS: You don't ask that?

MR. ROONEY: No. Maybe we should, but we're not. Dr. SerVaas, I think I'd amplify that one further. Those questions, similarly to questions about venereal disease are -- in my entire career in selling insurance, only once did I ever have a person admit to having had a venereal disease. That was a young boy about 19 years old. We know there's a lot more venereal disease than that. People just don't acknowledge that.

CHAIRMAN WATKINS: We're going to shift questions that any of the Commissioners may have that focus on Dr. Pascal so that he can move out then when he needs to for his travel.

I know that Mr. DeVos has one question. I'd like to focus on questions for Dr. Pascal now.

MR. DeVOS: I salute you, all three of you on your fine work in this. We're struggling with this whole matter of incidence and prevalence. We've had testimony on it from a variety of people. You come here with some very interesting data, I'm sure based on a lot of research you've done, cost analysis. While this is a cost group, it's got to be based on the incidence and prevalence estimate that you're making. CDC has estimates and you've come in here with this.

Dr. Sisk, you must have similar data that you have done to get some of your numbers out of that. Are you two close at all? I know you're sitting next to each other. Are you close at all on your numbers? Do you agree with each other?

DR. SISK: One thing that Dr. Pascal mentioned that I didn't, but is also true of the work that I've done, is that there's no original data collection that was involved in what I put together. What I did was look at estimates that were made in connection with other work.

The national estimates that I mentioned as the most rigorous and comprehensive by Scitovsky and Rice were based on projections of prevalence from the Centers for Disease Control. So, Scitovsky and Rice did not come up with any original estimates of prevalence.

All of the other work, that I can think of at this point was drawn from what was happening in a particular state or what was happening in a particular hospital, so there were no estimates there. It was a matter of going through records and as best anyone could detect after the fact, which is a big caveat, the various researchers enumerated the number of cases of AIDS.

MR. DeVOS: When I read your bio and all the history and all the great things you've done, I've just got to infer you know it all.

DR. PASCAL: I used a higher estimate of case load than CDC has been projecting for a number of reasons. There's been some work at RAND that's not finished yet in trying to model AIDS which takes into account not only extrapolations from what we now know about the incidence and prevalence, but also takes into account behavioral change and the natural history of the virus which CDC does not include in its estimates.

That combined with reading about the number of seropositives in the country and the conversion rates that people have been observing leads me to feel that the CDC case load numbers are on the low side. I did use them in my low estimate, but for my intermediate estimate, I used a higher number of 400,000, where theirs would come out to about 270,000 or maybe by 1992, 300,000. So my numbers are somewhat higher than CDC's for my intermediate estimate.

MR. DeVOS: Well, I'm very interested in your numbers and in your conclusions on costs and their allocation to changing age demographics. I tell you, that's very valuable information. We certainly are interested in your further work on costing that you're doing in the West Coast. It may not be in time for our report, but anything you can share with us will help us.

DR. PASCAL: Well, we hope to have -- this again is Health Care Financing Administration. It's sponsored this work through the RAND HCFA Center. And Penny Pine, who is sitting in the room here, has been instrumental in arranging for that. We are doing this pilot study in L.A. which will give us, we think, the best information that anybody has now got about how AIDS is financed. But it's only going to be one city and a small group, in fact, in this pilot. But by next year at this time, we'll have done five or six of these around the country and be able to say something much more definitive on financing.

MR. DeVOS: Well, let's face it, we're dealing with a moving target. We've got to go with a report on a certain date, but the data is changing so fast that we don't know. But you've got such a great reputation and high regard for the work you people do that we're very, very appreciative of that.

DR. PASCAL: Thank you very much.

CHAIRMAN WATKINS: Is it possible at this point in time, either through HCFA or you directly, to get some of the supporting assumptions and other things underneath the data or is that premature?

DR. PASCAL: We couldn't provide it to you now. I think by the end of the summer we'll have that.

CHAIRMAN WATKINS: I see. Okay. Thank you. Mrs. Gebbie?

MRS. GEBBIE: A couple of questions. Dr. Pascal, you mentioned that there is a substantial amount of self-pay.

DR. PASCAL: I'm so eager on this subject that I look at the questionnaires as they come in from this small panel in L.A., and I'm seeing a lot of self-pay.

MRS. GEBBIE: Okay. My question about that was whether you will be in a position to put that in any kind of perspective. I think there's a good deal of self-pay in almost every major illness that I know about. I would not want to look at the effect of that on AIDS patients in absence of information about whether that's typical or whether they have an unusual burden in that area.

DR. PASCAL: We won't be able to study anybody else directly, but we will relate it to whatever literature we can find on self-pays.

MRS. GEBBIE: My other question is, I'd like you to be at least one of the answerers, although others might have comment. I'm persuaded we're probably not going to get a whole lot of different information between now and our final report than the kinds of preliminary things we have to go on right now and that we will come up feeling somewhat frustrated. I think we may well want to say something about forward looking data collection that will allow future course corrections or changes.

Are there some things we should say or some recommendations we would make that would make the kinds of research you are trying to do easier, either policy statements or directions to federal agencies or directions to data sources that would make all of this better so that looking at this in 1990, say, we would have a much better data source?

DR. PASCAL: Well, one thing that does occur to me, because it was part of our original charter from HCFA but we weren't able to get very far on it, we're aware that many states are conducting studies. In California you've seen the reports that have come out. Other states are doing this as well. It's very hard to determine whether these state studies are on a common ground, using the same sorts of definitions, using the same sorts of estimation techniques and so forth. If they were, if the federal government could in some fashion give direction to the states or to encourage them in some way to do studies that are comparable so we could put these together when they're done into a national database on AIDS, number one I think that would be very important.

Number two, I think that you should commend the work that NCHSR has done in commissioning this cost methodology study by Anne Scitovsky, whose name isn't mentioned here, which will be coming out quite soon and should guide future work and give again common ground as to how things should be defined and estimated how samples should be selected and so forth. I think that's very important as well.

MRS. GEBBIE: Other comments?

DR. SISK: I think that the work that's been funded through the National Center for Health Services Research is supposed to be completed this coming fall. But that, as Dr. Pascal said, is going to be a methodology for collecting data, not the actual collection of the data.

One possibility, again building on what he said, would be for the Health Care Financing Administration to use those methodologies and require or offer funding for states to use that methodology to collect data and develop the necessary information. One hook might be through Medicaid programs. I can imagine that either certain sums of money could be made available to the states to do that kind of work, or it might even be a requirement of Medicaid participation.

DR. PASCAL: Yes, I think Dr. Sisk is absolutely right in what she's proposing. I also want to reiterate that I think there's lot's of really valuable information in insurance claims files. If the Commission could somehow suggest ways in which the companies could make those data available to researchers without violating confidentiality rules and without violating anti-trust and liability problems that the insurance companies are fearful about in providing such data, I think that would be an important step forward as well.

I think those data need to be analyzed, but the companies I think for both commercial and legal reasons are a bit reluctant about releasing it even to impartial researchers.

MRS. GEBBIE: Neither of you said anything about broadening the questions to include the full spectrum of HIV infection rather than just focusing the studies on diagnosed AIDS. Is that something you've encountered?

DR. SISK: I did in my original statement.

MRS. GEBBIE: I'm sorry. Maybe I missed it.

DR. SISK: There is another problem that I don't recall whether I mentioned before with developing information on the cost of any medical condition in this country. The data, like our health care system, are fragmented. So it's very difficult to get a comprehensive picture. One has to piece together data from different sources to get the total cost of any particular condition. Any studies that would be funded through the federal government would be well advised to use and to support methodologies that would get that comprehensive picture.

A very simple problem is putting together physician and hospital costs and identifying costs that are accounted for by particular diagnoses. Some methodologies are being developed specifically for AIDS. But these are general problems that should be attended to.

DR. PASCAL: And in both the work that we are doing with the patient panels and in extensions of that work and, if it's feasible, with insurance claims data, we would look at pre-AIDS expenses, expenses that had been incurred by patients before the official diagnosis. So, we hope to get at that as well.

MRS. GEBBIE: I think we're very reluctant to sound like we're putting money other than into direct services, but sometimes you need back-up information in order to spend the service money well. Are we putting approximately the right proportion of our resources into the kinds of questions you could help us answer or are we, in fact, short changing ourselves on this end in order to think we're doing something?

I know all researchers always want more money. We'll discount it for that regard now.

DR. PASCAL: From what I hear about fiscal '89 funding for AIDS research, it looks like it's getting closer to the right level. I think it's been short up until now, but I'm hoping that '89 will be a lot better.

MRS. GEBBIE: Could the two of you collaborate in writing out for us the five most important things in this area that you think we should say in our report? Who knows what we will say, but I think if we could see through your eyes what would be helpful in this area. Thank you.

CHAIRMAN WATKINS: Just as a quick follow-up while we've got you here, Dr. Pascal. Is HCFA your only funding source?

DR. PASCAL: I'm sorry, I didn't hear you, Admiral.

CHAIRMAN WATKINS: Is the Health Care Financing Agency your only source of funds?

DR. PASCAL: At this point, yes. We have a proposal into National Center for Health Services Research for this New York study and we're preparing proposals for the insurance study and for the additional cities on the patient panels and we're not sure yet where those will be submitted.

MRS. GEBBIE: I do have one more question.

CHAIRMAN WATKINS: Yes.

MRS. GEBBIE: One other thing I almost forgot. I can't follow my own scribbles here.

I've at least had some trouble following who all is involved in various parts of this research. I guess it was last week, we stumbled across another whole set of research on modeling the epidemic that involves the Bureau of the Census and AID, I think, or one of the other federal agencies. Are you familiar with how they fit into what we're doing? I had looked at mostly CDC based data then being pulled out.

DR. PASCAL: I'm familiar with the university activities and CDC and RAND's own, of course, but I had not heard about a Census Bureau modeling effort. With AID, the foreign aid people?

MRS. GEBBIE: Yes, that's who I think it was. They indicated, at least, that they're --

CHAIRMAN WATKINS: Also, the Center for Population Options was involved in it.

MRS. GEBBIE: They indicated that they had been involved in some substantial critique of the modeling efforts with other agencies and so on?

DR. PASCAL: This is for getting world wide estimates of case loads, do you think?

MRS. GEBBIE: Yes. Are you familiar with that effort?

DR. PASCAL: I'm not.

CHAIRMAN WATKINS: This points up, though, one of the reasons why your recommendations to us become very important. If we're launching off on a lot of these studies independent of each other, you know what that means downstream for chaos. We asked the question of the effort to try to get a global picture on this modeling. Is there within that model an element that can be tried here in the United States so that the sub-element in their modeling techniques would give us good results?

The question is about modeling. We got turned off a little bit about modeling because it doesn't sound like you're interested in people. But from the financial point of view, we think it's very critical. Certainly, we think the right people ought to be together. Maybe in your recommendation you can say, "Who are the right people to pull together the various elements," so that our representative at the World Health Organization in the AIDS task force there, Dr. Jonathan Mann, has the benefit and we have the benefit of their input as to what their modeling concepts might be.

DR. SISK: If I understood the point you're making, I'd like to make another one, although ultimately coming up with estimates of the total costs of AIDS requires information from somewhere about the number of people who were going to be affected, nevertheless there are two efforts going on and that can go on independently, at least for a while. People can be collecting data on the costs of treating AIDS separately from people who were putting together models to predict the spread of the epidemic.

For example, at a conference I think it was last fall, sponsored by the Institute of Medicine on modeling the spread of

AIDS, which had people from other countries as well as the United States, there seemed to be a consensus, if not unanimity, that modeling the spread of the epidemic was at such a rudimentary point that it was really preferable to let a thousand flowers bloom, to have many different researchers working on the elements to put into the model instead of coming up with one favorite model at this point. The feeling was that it was premature to do that, at least at that point, and I would think at this point as well.

But these two efforts could go on simultaneously with the intention that ultimately they could come together.

CHAIRMAN WATKINS: If you have a long term objective that you're looking for the ultimate model then you need a strategy that says, "This is what's doable today, but we ought to be more aggressive. We ought to go after this information, we ought to keep working towards that final objective." We'd be very interested in that sequence of events as you see it. Then your ideas of how we would focus resources to achieve those long term, mid-term and short-term objectives. It seems to me that's what we ought to do, not try to say, "Now it's so big we can't handle it."

DR. PASCAL: I'd like to express a slightly different take than Dr. Sisk on the coordination between modeling and case load forecasts and cost studies. I think that they are independent efforts except at one point, that the sub-populations you look at in both have to be the same. In other words, if the case load numbers are going to come out in terms of IV drug users, gay/bisexual males, pediatric, other heterosexual transmission, then you have to do the costing on those same categories in order to put the two together. So, to that extent, coordination is called for, I think.

MRS. GEBBIE: One other request to Dr. Sisk. If you have a written report of that meeting you participated in last fall that looked at models, we've gotten so much paper, but I don't think we've seen that. It would be helpful.

DR. SISK: I don't have whatever report came out of there, but I could ask people from the Institute of Medicine.

MRS. GEBBIE: Or point us in the right direction to find it.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: I wanted to bring up that point that you just stressed there a little bit. I was quite fascinated in the written material that you provided for us in our briefing books, Chart Number 8 and 9 in which you compare the --

DR. PASCAL: I'm sorry the reproductions are so bad, but it's in my HCFA report, the same table.

DR. LILLY: Right. I was quite struck by the fact that what you're doing actually is comparing the period of disease of a 35 year old homosexual of middle income with a 30 year old intravenous drug user who is destitute. You come to the conclusion, for example, that the total cost of medical care are inversely proportional to the length of life following diagnosis essentially.

DR. PASCAL: Yes. These are hypothetical cases to illustrate your point.

DR. LILLY: They're hypothetical, but I assume you have some basis for this.

DR. PASCAL: Yes, much heavier hospital care typical of the drug users because of no alternative sites to provide care in. That's the main consideration there. And much poorer physical condition when the drug user comes down with AIDS, which exacerbates his medical problems.

DR. LILLY: Right. Well, I think these two charts are very interesting. The other question that I'd like to bring up is cost variations over calendar time. Do you have any information about how the cost of AIDS has evolved from 1982, say, to 1988 and any projections as to -- for the same type of person.

DR. PASCAL: Yes. Right. I think that's the only good news about AIDS, is that the lifetime costs have been falling rather substantially. Ann Hardy's figures of $150,000, despite any complaints people might make about methodology, still the costs were very high at the period that she was studying the disease. I think they have come down substantially on a lifetime basis, no matter what you control for, means of transmission or pathology or diagnosis.

DR. LILLY: Do you expect that to continue into the future?

DR. PASCAL: No, I think it's -- I talk to a lot of people who study these things. They're beginning to see kind of a plateau now in the last year or so. They've come down to the $50 to $70,000 range lifetime. I don't hear many reports, except in San Francisco, of costs much below that. That includes inpatient/outpatient, home care, drugs and all the rest. It could be that some new intervention will occur that will get us below that plateau, but I think we've been stuck there for a year, 18 months.

DR. LILLY: And what is the influence on this -- it was something you referred to, but I didn't quite catch in what sense -- the influence of the prolongation of life that is taking place now, to some extent under the influence of AZT treatments and which hopefully will continue to --

DR. PASCAL: I would only be able to speculate here. I've not seen any direct studies of the relationship between AZT and lifetime costs. But from the people that I talked to, they think it's a wash or that it's caused a slight increase in costs because of the increased survival time which means over time that even though you've spent fewer days per month in the hospital, you're alive enough more months that the total hospital costs really don't decline. When you add the treatment of the side effects, the extreme anemia and transfusions and so forth. Some of these patients, they think if they live long enough, they'll have to do bone marrow transplants to combat the anemia.

Then the cost of the drug itself is now $8,000 a year. I think that the total effect of AZT has probably been to increase costs to some extent.

DR. LILLY: Thank you.

CHAIRMAN WATKINS: Dr. Lee, you have a question for Dr. Pascal?

DR. LEE: I'm very interested in how economists come up with this indirect cost business. It's getting very fashionable now in the AIDS world to talk about future lifetime earnings and these indirect costs. What is the multiplier? How do you come up with that? Why don't we calculate how many suits he would have bought over 50 years or something? I mean why is this of any meaning to us? Why don't we compare it to the indirect costs and earning capacity loss of the common cold or the stubbed toe or falling off ladders? I'm just being cynical. Aren't you inflating the numbers here to make a point that is a little flaky?

DR. PASCAL: Well, I haven't done these estimates myself. But if I could defend my profession a little bit, I think people have done these sort of human capital approaches to disease costs for many different diseases, coronaries, cancer and auto accidents and many other kinds of diseases and try to take account of the product that is not produced as a result of the morbidity or mortality that occurs. People's working lives are interrupted or ended in their prime working age and all of the things they would have produced don't get produced.

Now, I think you're right to make the point that you did about how many suits would this person have bought. The AIDS population is peculiar in this country compared, say, to auto accident victims or cancer victims or coronary victims in that on average they have fewer dependents than would the typical auto crash victim. Well, maybe not auto crash because those are mostly young men before they marry. But say the coronary. So, they might have fewer dependents because of their socio-economic and demographic situation.

So, if you were to calculate a net loss, that is the production loss minus the consumption that would have occurred by that same production, you might come up with a smaller figure because of a smaller number of dependents. But still, it would be substantial, I think, even the net product loss and it would be many time what the direct medical cost would be.

DR. LEE: Well, who is interested in the figure?

DR. PASCAL: Well, I think as a nation we're interested.

DR. LEE: Are the people calculating the GNP interested in it? Is that it?

DR. PASCAL: I didn't hear you.

DR. LEE: Who is interested in that total loss, et cetera? Is it GNP people, is it OMB? Are we interested in that figure?

DR. PASCAL: I think you should be. It seems to me that the way the nation allocates its health care resources should partially reflect the savings that are going to be made on an national basis in terms of these kinds of social costs.

DR. LEE: Well, unless we cure the disease, I'm at a loss to see the true relevance of it. Congress doesn't have to raise money for that. We don't have to allocate any funds for that. Anyway, let's get back to the basic health care costs. AIDS is two percent of the total health care cost? Is that the figure?

DR. PASCAL: That's my forecast into the 1900s, yes, on a cumulative basis.

DR. LEE: So, in your mind, this is an impressive number? Is this something that is going to really rock the boat?

DR. PASCAL: I don't think it will destroy our health finance system, no. But I think the numbers are significant enough that we have to pay close attention to it and to try to minimize the resource costs that are involved, sure.

DR. LEE: Okay. I could explore that a lot further, but let me get to the last part. The second part of the two questions here, how much, which I really wonder about all these figures, how meaningful they are. But the second one is more critical to us, I think, and that's who should pay. Okay? Who should pay?

DR. PASCAL: I think that we should depend as much as we can on the private health care system to cover as much of these costs as possible, as we do with other diseases, and that we have to have the public system as a backup, Medicaid and the VA and maybe eventually Medicare, I don't know, to deal with people who have no recourse to private health policies of these kinds. What should be the fraction? How much should each pay? I don't think--

DR. LEE: The pressure is on us to do AIDS differently. Should we be doing it differently or should we just use the regular system here and modify it?

DR. PASCAL: I think there are some important modifications such as the home and community waivers for Medicaid so that people can get treated at home at a lower cost and in a more satisfactory way, for example. I think that we should extend the Comprehensive Omnibus Budget Reconciliation -- the COBRA system so that it protects people for longer periods and also that it protects members of small groups.

DR. LEE: Well, we got all those. And in general, what you're doing is all four of you are saying that you agree with these alterations in the present system. Is that correct?

DR. PASCAL: Yes.

DR. LEE: We're not looking for the taxpayer to pay for this or the government to pay for this? You're not looking for any dramatically different solution here?

DR. PASCAL: No. I don't have a magic figure in my mind that the taxpayer should pay 70 percent and the insurers 30 percent. I don't see any basis to come up with such an end result as that.

CHAIRMAN WATKINS: We're informed, Dr. Pascal, that you must leave.

DR. PASCAL: I have a plane to catch.

CHAIRMAN WATKINS: Your presentation was excellent today. The mistake you made was telling us you had to leave at 5:00, so you got all the questions, and nobody else has had to say anything. But anyway, thank you for coming here. We may want to follow up with you because this is one area of weakness that we have found, getting the hard information we need on cost analysis. I think you might have heard some of the discussion before this panel came on. So, thank you for being with us.

We'll start back on my right with Dr. Conway-Welch for any other questions she may have for the other panelists.

DR. CONWAY-WELCH: I had two questions. I'd like to address the first one to anyone who'd be interested in trying to answer it. Perhaps this isn't quite the right group, but can you give any kind of a synthesis or a summary of the Medicaid waivers that are being suggested and talked about in terms of providing some efficiency in the Medicaid system.

While you're thinking about that, I would also like to ask Mr. Thompson a question regarding this chart that he spoke of with the 24 admissions. The room and board category accounts for 50 percent. I wanted to make sure I understood your statement. Did you say that half of that 50 percent accounts for the nursing piece or that the 50 percent accounts for the nursing piece?

MR. THOMPSON: Half of the 50 percent.

DR. CONWAY-WELCH: So, 25 percent of the total services are actually nursing and 25 percent are the room and the food. Thank you. Could I go back then? Do you have any information in terms of the discussions that are circling around regarding Medicaid waivers or is this not the appropriate group to address this question to?

MR. THOMPSON: I don't have too much information because Connecticut has done voluntarily most of the programs that other states have applied for waivers for.

DR. CONWAY-WELCH: I see.

MR. THOMPSON: AZT funding, for example, and beefed up home care. They have tried managed care in three localities in Connecticut. I know that they are putting in for a waiver to continue the managed care, but that's about all that Connecticut is doing.

DR. CONWAY-WELCH: Okay. I'll address that to another group.

MR. THOMPSON: I think there's one question though that Dr. Gebbie brought up. That's this question about is Medicare a quick fix for your problem?

DR. CONWAY-WELCH: Right.

MR. THOMPSON: I don't think Medicare is a quick fix for your problem for a couple of reasons. One is the incentives are all wrong. The incentives under Medicare are to hospitalize patients. The only way we can make any kind of push on AIDS is to keep patients out of the hospital. The present Medicare ambulatory benefits and home care benefits are not strong enough to enable us to really move patients out of the hospital.

Somebody else spoke about the absolute lack of Medicare payments for nursing homes. So, that's no quick fix. I know that you're under pressure because somebody will say, "Well, we fixed ESRD this way. We'll fix AIDS this way." I think that's a slippery slope, if you don't mind my saying so, unless you really want to radically change Medicare and the economies, the economics of Medicare won't let you radically change Medicare.

DR. CONWAY-WELCH: Thank you.

CHAIRMAN WATKINS: Dr. SerVaas, you have any further questions for the panelists? Mr. DeVos?

MR. DeVOS: No, I'm pretty well set, I think, Admiral.

CHAIRMAN WATKINS: Mrs. Gebbie?

MRS. GEBBIE: No, I think I've got it here.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: I don't think I'm going to be able to come to grips with this.

CHAIRMAN WATKINS: Mr. Thompson, at least I was struck by your closing statement because it hasn't been put quite that powerfully to us today. But your data seems to be compelling. Basically these individuals for the most part are in the hospital for nursing care, which could be provided elsewhere at lower costs.

Can you take the data you have here and convert me to the alternate concept? Have you done a comparative analysis on that which takes you from the data here and displays it with that of the alternate health care sites. How would this whole picture shift then? What would be the profile on that one slide that you've given us?

MR. THOMPSON: Well, you would keep the hospital only for those cases that really needed a hospital's unique facilities. In other words, the unique facilities that these people required were oxygen. You can give that at home. Laboratories, you can send the stuff down to the corner for laboratories. We were struck by the absolute lack of high tech charges in the hospital bill.

Now, this is not unusual. We find this in, if you don't mind my saying so, DRG 147, which is cardiac shock where the patients are in a hospital because they have not been able to make it at home. They become decompensated at home. They're brought back in and it's all nursing. It's watching them, giving them the drugs at the right time and that sort of business. We've got to start thinking of hospitals as very super intensive care units and limit admissions to those people who need those high tech resources.

CHAIRMAN WATKINS: Well, I think we agree and what I'm trying to do is get a more definitive projection of what we might have. Now, you testified once before in which you had a very exciting concept of information exchange between a number of entities that really had not communicated well in the past. The primary health care provider would have an opportunity to make a cost effective selection for the patient.

So, I'm trying to go from your last discussion with us to the conclusions you gave us on this particular occasion and pull the two together.

MR. THOMPSON: Well, let's address a question that you addressed to the last panel and this is the "cost effectiveness" of home care. You were concerned that there were many hidden costs in home care that didn't come out and therefore when people said $100.00 against $1,000.00, they were loading the dice.

This argument has been with us for a long time. You have to start both groups out on an even playing field. When a patient goes to a hospital, the family still pays rent. All the family expenses still go on when the patient is in the hospital. When the patient leaves the hospital and goes home, that money is still being spent. So, you don't have to worry about rent, you don't have to worry about -- maybe a little extra food.

What you do have to worry about, which somebody brought up, is the value of the services rendered by the relatives because don't kid yourself, home care depends on a supportive home. It's extremely difficult without it.

Now, we will begin to learn those costs for the first time with some of the new AIDS programs where we have to provide homes for people who don't have homes. In other words, we are now going to be giving home care in a substitute for the home. The people from New York spoke about their substitute for the home and there are other such places coming up primarily through the pressure of AIDS. There's a cottage just beginning, for example, in Connecticut. We will now know how much it really costs to keep people in their homes. We can add that on top of the home care costs and answer some of your questions about is it effective or not.

But up until now, the costs have been the same whether the patient is in the hospital or here, the social costs and all the rests of the support costs, the family costs.

What we've found was that those differences were fairly real. Now, some people have suggested that we pay the family for the care. That, I would think, would be a very good way of strengthening home care. We would pay members of the family for care. It would still be very cost effective.

So, those are the kinds of situations I understand you're in. But I think you're kind of overemphasizing them. But we'll find out when we get the data from the homes now that we're studying.

CHAIRMAN WATKINS: I don't want to mislead you. I'm a home care fan. What I was trying to say, I think the last time, was that we have witnesses come before us that say you've got to be cautious about your cost analysis. So, all I'm trying to do is find the ammunition to counter that in such a way that we can show exactly what we're talking about in all of its ramifications so that we don't have that constant rejoinder coming up criticizing our recommendations.

MR. THOMPSON: I couldn't agree with you more. The best frame that you can figure that out in is what are the additional costs for home care.

CHAIRMAN WATKINS: Right.

MR. THOMPSON: Not the costs that the family has got already. That's the only way you can look at it. If a person has to quit their job to take care of that person, then that's an additional cost that's got to be replaced. If the father or mother --

CHAIRMAN WATKINS: Is that factored into your information interchange program that you were telling us about before?

MR. THOMPSON: That's going ahead. In Connecticut, we've accomplished the first task which was try to match DIMS data with Department of Health data. I've told you there are nine agencies up there, all of whom have a piece of the action. They all have their own information systems and they're not at all compatible. We are getting a grant from Connecticut to set up a single access, single entry system to preserve anonymity that will gather data from all state agencies. That's one place where we'll begin to do some of these kind of studies and some of these program plannings and we will be depending upon Mrs. Scitovsky for some of the cost data when she gets her report out, although we would use a DRG model.

MR. DeVOS: I think, Mr. Thompson, one interest in this is to support the system to where the person with AIDS will return home, to their parental home, wherever that was. If those providing home care would just break even in some form to do that, we think that's all our ideal solution wherein sick people would have a place to return to. That would break up, to some extent, these groupings where so many of them end up homeless in these major centers where they drifted to at a different time in their life. They would be encouraged in a different way to go back home where they came from, where they can get good home care. So, we're very interested in what you're working on and we're right on board with you.

MR. THOMPSON: I would only add one thing. A home or a substitute for the home.

MR. DeVOS: Either way. I mentioned the substitute home because I know they won't all be able to go back. I look at a substitute home. How far can you move them away from where they're living? The cost in West Virginia or someplace may be a whole lot different than those costs of keeping them comfortably in New York City. That's a psychological thing that's very difficult to deal with and you can't treat that purely as a cost function. But we're going to have to examine that.

MR. THOMPSON: We are treating one-third of the AIDS cases in Connecticut at Yale New Haven Hospital simply because we have a very active clinic and word gets around. So, people from Connecticut and even New York come up for treatment. You can't turn them away.

MR. DeVOS: No, but let's assume you work towards where there was adequate support in a different community.

MR. THOMPSON: I don't have to tell you. You've had enough witnesses tell you this. There aren't that many places where discrimination doesn't exist, where programs are known and publicized and where you have a sympathetic staff that's always reaching out for new patients. There just aren't very many of them around.

MR. DeVOS: I agree with you historically, but I think we're also into a fast changing scene where those things do move differently. That line of sympathy is expanding, not diminishing in my experience, as people know how to handle the HIV epidemic and cope with it and I think you'll find that more reaching out in other parts of the country. I hope.

MR. THOMPSON: So do I.

CHAIRMAN WATKINS: Any other questions?

DR. LILLY: A comment. I'd like to comment to Mr. DeVos and remind him, as he already knows I'm sure, that in fact, particularly among the homosexual population, a lot of them are not welcome back home.

MR. DeVOS: I understand that, Frank. That's why I think of the alternative. You can answer it maybe better than anybody else. Does it have to be right here or if there's a group, can they be as comfortable, maybe even happier in a different setting? Is that a major psychological break or not?

DR. LILLY: Well, if you're worrying just about the cost, then maybe we should ship everybody back to someplace where it's cheap.

MR. DeVOS: I told you I wasn't worried just about the cost. I was trying to evaluate both of them. It's like saying, "I want to live in New York or I want to live in the Plaza," when you have never lived there and you can't afford it anyway. A lot of those people didn't come from there.

MRS. GEBBIE: But a lot of people chose to live where they were living when they became ill. I think when we want to ask that question we should ask it of ourselves. If you became ill today, how far away from where you now live would you like to be relocated? I'm not sure that the question for the patients diagnosed with this disease is terribly different than it would be for any one of us.

MR. DeVOS: I wrestled with that one. But if I also am homeless, then I've got to make some new friends someplace.

MRS. GEBBIE: Yes.

MR. DeVOS: Then I maybe have to take another look at it.

MRS. GEBBIE: But I don't think that's uniquely different to AIDS patients.

MR. DeVOS: No. Oh, no, I agree.

MRS. GEBBIE: I think that cuts across a whole bunch.

MR. DeVOS: But somebody else is paying the bill. When you're there, you're paying the bill. When somebody else pays the bill, they're going to ask these questions. If the