TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

* * *

HEARING ON

FINANCING HEALTH CARE

FOR PERSONS WITH HIV INFECTION AND AIDS:

POLICY OPTIONS

* * *

Pages 1 thru 247

Washington, D. C.
April 22, 1991

MILLER REPORTING COMPANY, INC.
507 C Street, N.E.
Washington, D.C. 20002
546-6666

NATIONAL COMMISSION

ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

FINANCING HEALTH CARE

FOR PERSONS WITH HIV INFECTION AND AIDS:

POLICY OPTIONS

April 22, 1991

9:00 a.m.

Pan American Health Organization Building

Conference Room B

525 Twenty-third Street, N.W.

Washington, D.C.

MILLER REPORTING CO., INC.
507 C Street, N.E.
Washington, D.C. 20002
(202) 546-6666

COMMISSIONERS PRESENT:

June E. Osborn, M.D., Chairman
Diane Ahrens
Scott Allen
Harlon L. Dalton, Esq.
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Don C. DesJarlais, Ph.D.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
David E. Rogers, M.D.
Hon. J. Roy Rowland, M.D.
Michael R. Peterson [Representing Hon. Dick Cheney]
Irwin Pernick [Representing Hon. Edward J. Derwinski]
James R. Allen [Representing Hon. Louis W. Sullivan]

COMMISSION STAFF:

Maureen Byrnes, Executive Director
Frank Arcari, M.P.A.
Thomas D. Brandt, M.L.S.
Adriana Carmack
Lu Verne Hall
Jason Heffner, M.Ed.
Carlton H. Lee, Jr.
Melanie Lott
Lee Marovich
Joan A. Piemme, R.N., F.A.A.N.
Karen Porter, J.D.
Nicole Ryan
Jane Silver, M.P.H.
Patricia Sosa, Esq.
Jeff Stryker

C O N T E N T S

Presentation by the Johns Hopkins University
School of Hygiene and Public Health
Department of Health Policy and Management
624 North Broadway
Baltimore, Maryland 21205

Karen Davis, Ph.D.
Ron Bialek, M.P.P.
Chris Beyrer, M.D.
Patrick Chaulk, M.D.
Rose Chu, M.B.A.
Peter Cowley, M.D.
Jennifer Harlow, M.H.S.

P R O C E E D I N G S

CHAIRMAN OSBORN: Good morning and welcome.

Hi to everybody that I haven't had a chance to say hi to. Sorry that we are running a bit late getting started, but people's travel schedules have been complicated I think, and I'm delighted to welcome everyone.

I want to mention that we have asked several of our experts and consultants to join us at the table this morning. Dr. Phil Lee will be coming quite shortly. Tim Westmoreland, welcome. Harvey Makadon, Bob Fullilove, Molly Coye, Pat Franks, Jeff Stryker, and, of course, Karen Davis, who will be starting things off.

We are very pleased that Congressman Rowland can be with us to start the morning. One of the reasons I'm eager to get us started quickly is that his Congressional schedule is going to press him to have to leave us after a bit, and he will be here part of today and part of tomorrow, and that's always an extra effort I think. Especially it is hard when both things you have to do are in Washington.

We have asked Karen Davis to help us in this discussion this morning. Before we get started, David, do you have any comments you would like to make?

COMMISSIONER ROGERS: No, just to welcome all those distinguished guests. I just think we don't need a Commission if you would like to write our report for us, but it is nice to have all of you with us. Thank you.

CHAIRMAN OSBORN: Karen, let me just turn the floor right over to you, and thanks for being with us and for your good work.

DR. DAVIS: Thank you. We are delighted to be here this morning and to have a chance to talk with you about approaches to financing health care services for persons with AIDS or HIV infection. You have received a somewhat lengthy document. I hope you have had a chance to look at that. There is also an executive summary that highlights some of the major points in the report. We have also distributed to you a set of charts that we would like to go through to summarize what we think are some of the main reasons why this is such an urgent problem requiring attention, and then to lay out for you some options that you may want to consider as possibilities to select from for recommendations in the final report of the Commission.

I'll be assisted today by a team of people who have worked on this report, and I'd like to start by introducing

them. We have today Ron Bialek, who is an instructor at Johns Hopkins and head of our health program "Alliance," our program that tries to assist state and local health departments with major issues. Also Dr. Chris Beyrer, who is a preventive medicine resident at Johns Hopkins, who is with us. Dr. Patrick Chaulk, who is an instructor and chief preventive medicine resident at Hopkins; Rose Chu, who is an MBA from Actuarial Research Associates, who has been responsible, with the principal, Gordon Tracknell, for much of the cost estimates that you see in your report; Dr. Peter Cowley, who is also a preventive medicine resident who has worked with us on the project; and Jennifer Harlow, a research associate in the Department of Health Policy and Management at Johns Hopkins.

We are going to highlight some of the major findings in our report, but I'd like to stress that we would very much like an informal presentation. I think you have had a chance to summarize or view this quickly at least, if not in depth, so please interrupt us, ask questions. We are happy to respond as we go along. And we also feel fortunate to have a number of knowledgeable experts here today and hope that you will also raise questions and concerns as we

proceed.

I'd like to begin by summarizing what we know about who it is that needs services for the care of HIV infection or AIDS and what we know about the total cost of that care. And for that I'd like to turn to Dr. Peter Cowley, who has worked on this. So we will be going through some of the early charts in your packet.

DR. COWLEY: If we could turn to Chart 1 where we have the chart of persons with AIDS, we see 1990, 117,000 persons with AIDS; in 1991, 140,000; 1992, 164,000; and in 1993, 188,000. The source of this data were projections as well as MMWR 1991.

Turning to Chart 2, persons with HIV infection, HIV estimates range from 700,000 to 1.5 million. There is a consensus to these numbers. However, as you can see, it is a range. Approximately one million HIV infected as of 1991. This was from the Centers for Disease Control.

New infections are estimated at 80,000 in adults -- again, this is from CDC -- and 1,500 to 2,000 newborns per year, and again, this is from the Centers for Disease Control.

The incubation period is estimated to be 11 years,

again, the median, and the range is from six months to 24 years. To the best of our knowledge, it should be mentioned that the persons with new infection, the predominant proportion of these people may contract AIDS despite current therapy.

The median on the incubation period was from a San Francisco cohort as well as military studies as well as transfusion recipient studies.

COMMISSIONER ROGERS: Dr. Cowley, in terms of the 700,000 and 1.5 million, those, of course, are figures we have had for about five or six years. Has anybody ever looked again? I mean, that has been just a constant estimate and yet we have these new infections moving along.

Has anybody really updated that, or is that dated?

DR. COWLEY: I haven't seen any. However, I'll refer to Dr. Beyrer, who has done the actual work on this. I did the cost studies and Dr. Beyrer did some of the population studies.

DR. BEYRER: As you probably know, there was an attempt within the last year to look at doing a seroprevalence survey across the states to determine, really to get a better handle on that number. And after doing the

pilot studies for it it was abandoned by CDC. So the figure of a million is actually based on back calculation, and the problem with the new number is that the incubation period may be changing and the time from progression from HIV infection to AIDS hopefully is being changed by early intervention. So we used the older number really because the newer numbers are much softer, unfortunately. So as the epidemic changes, the estimates are getting weaker.

CHAIRMAN OSBORN: Jim Allen, you may want to comment too.

MR. JIM ALLEN: David, in fact the number of one million is actually a fairly current estimate. That was made in late '89 and refined in the early months of 1990, so it is just about 12 months old. At that time that they recalculated this they went back and looked at their 1986 estimate based on currently available data, and they clearly stated that their '86 estimate was an overestimate, that that should have been something on the order of three-quarters of a million. So between '86 and '89, the end of '89, we had an increase of about 250,000 infections estimated. And in actual fact, those estimates are based on two sources; one, the back calculation method that was just referred to, and

the other is taking all of the seroprevalence data from the family of surveys, estimating populations, adjusting for differences around the country, and then cumulating.

And using that method along with the back calculation, they both come out within a few thousands of each other. It is remarkably consistent.

DR. COWLEY: If we turn to Chart 3 we will see the changing population of AIDS. Between 1981 and 1986, intravenous drug users constituted 17 percent of the AIDS population, while homosexual, gay/bisexuals, constituted 63 percent. In 1993, we see the intravenous drug users went up to 28 percent while the gay/bisexual population constituted 57 percent.

The "Other" category has stayed stable at between 20 and 21 percent. It should be mentioned that the "Other" category includes hemophiliacs, heterosexuals where transmission was unknown, as well as other blood recipients.

Chart 4, we see the distribution of the cases. Five states -- New York, California, New Jersey, Florida and Texas -- accounted for 59 percent of all cases of AIDS diagnosed from March 1990 to February 1991. It should be mentioned in 1988 these five states accounted for

approximately 69 percent of cases. While this is changing, one can still see that the burden of the AIDS cases is still on a very few state area.

Point two, the large majority of cases are in urban centers -- New York City, San Francisco, Los Angeles, Newark, Miami, Washington and Houston.

As the epidemic turns towards the intravenous drug using population, these cities will be particularly hard hit again as a lot of intravenous drug users tend to live in urban centers.

If we turn to Chart 5, the costs of the HIV epidemic, the estimated total cost of AIDS is approximately $8 billion. This is in 1991 dollars and it is based on prevalence-based studies. These figures were taken from a Hellinger study as well as other studies from a year or two ago and inflated upward. The annual treatment costs of an AIDS patient is approximately $75,000. This is in 1990 dollars. It should be mentioned that the annual treatment costs vary year by year quite substantially as AIDS treatment modalities change. The prevailing treatment method has been towards shortening hospitalizations and shortening the time of hospitalizations. There has also been a lot of differing

figures for drug treatment costs from year to year.

The estimated annual costs of treating HIV positive individuals needing treatment is approximately $5,094 dollars in 1990 dollars. It is estimated that approximately 60 percent of HIV positive persons non-AIDS will benefit from treatment, and predominantly AZT at this moment. Of that proportion, one-third would benefit from Pneumocystis carinii prophylaxis, which includes pentamidine.

Chart 6, the expected future cost increases of the HIV epidemic. The proportion of AIDS cases caused by intravenous drug users is rising, and it is expected to rise in the future, with resultant cost increases, especially in the public sector. The reasoning for this, the intravenous drug using population. In that population their health status is generally poor, the incidence of outpatient treatable disease is comparatively low as compared to previous study populations of the gay cohort in San Francisco, who tended to have a lot of outpatient treatable Kaposi's sarcoma. The intravenous drug users often tend to have more inpatient treatable disease, i.e. Pneumocystis carinii pneumonia. And in general, intravenous drug users have poor health insurance status, which will result in cost

increases for the public sector.

Thank you very much.

DR. DAVIS: Any questions on the cost estimates there?

Well, I think we all feel a little uncertain about any of these numbers.

MS. BYRNES: Does the $5,000 figure include pentamidine as well as AZT?

DR. COWLEY: Absolutely.

CHAIRMAN OSBORN: Other questions? We will probably be coming back, but that's very helpful. Thank you.

DR. DAVIS: We have probably given more certainty to these numbers than we feel. I think if you will look through the text you will see there are a lot of conflicting studies and CDC tends to put out ranges for their counts of people, so this is our best estimate of what we are talking about in terms of people and the cost of treatment.

As we turn to the issue of insurance coverage we feel even more uncertain. I was a little bit shocked to find how difficult it was to get any good sense of where people are with regard to health insurance coverage. We have made our best guess at it in the text and in Chart 7, where as

best we can tell, about 40 percent of the population with AIDS have Medicaid coverage.

We went through the different programs last December in terms of how people get qualified for Medicaid, Medicare, and private insurance, and many of these are people who maybe didn't get on Medicaid early on in their disease, but as they exhausted their savings, their assets for the care of this disease, they would then spend down into Medicaid coverage.

So the Health Care Financing Administration does estimate that they are picking up through the Medicaid program for 40 percent of all persons with AIDS. So that part of this pie chart we feel the most comfortable with. How many of the remainder are covered by private insurance is much less certain. It seems that about 1 to 2 percent of the population of people with AIDS are covered by the Medicare program. We are roughly estimating that about 29 percent of this population are covered by private health insurance, but that is very difficult to get a firm handle on. It obviously varies a lot geographically and by population group, with Medicaid coverage much more extensive in the northeast than it is, for example, in the south.

The remaining population in terms of insurance coverage we show as uninsured. Obviously some portion of that population have access to services, for example, through the Veterans Administration. Others may be able to get care through public hospitals or clinics. But in terms of an insurance card that would permit you to get care at any provider of health care services, we estimate that roughly 29 percent of this population is uninsured. But we put a fairly wide band or range on those estimates of insurance coverage.

Turning to those with private health insurance coverage, again it is very difficult to get a good sense of spending. I saw one estimate that around 1.8 billion was spent by private insurance on the care of persons with AIDS in 1990. But again, I don't know how much confidence to place in that estimate.

In general, what we are talking about when we are talking about when we are talking about private health insurance coverage are persons who have gotten that coverage through an employer-sponsored plan. They would qualify automatically for coverage under those plans, either before or after being diagnosed as being HIV positive, for example. In general, large employer plans do not exclude people by

reason of health status either initially or after they contract a disease, and they would retain their coverage through those plans.

There are more problems when you get to smaller firms and to individual plans. Underwriting practices are quite typical in the small group market. So if someone, for example, is already HIV positive, they could be denied coverage at all under that plan, certainly would be denied coverage under individual health insurance coverage. Even a small group, once somebody contracted the disease and this was known to the insurer, could drop that group altogether at the end of the year, could hike the premium. So that there are various practices in the small group market and individual market that could exclude people with HIV.

COMMISSIONER ALLEN: I have a question. How prevalent is the insurance cap for specific diseases now?

DR. DAVIS: You know, we are starting to read more anecdotal evidence about that. I think there was coverage of that in a story in the New York Times or the Washington Post in the last few months.

Again, in general, if we step aside from the HIV/AIDS problem, insurance coverage has been running in the

other direction. Employer plans have increasingly either been offering coverage with no limit on benefits, or increasing the limit up to a million dollars. So that most large group insurance does not have specific dollar limits on services.

Again, in the individual market that's much more typical, or a small group market. But what we have been hearing about, and I'm sure you have heard about as well, is that employers are limiting certain services for the care of HIV or AIDS patients, that do put specific dollar limits on that, and just how common that practice is I don't know. It is just so far very anecdotal.

Turning to Chart 9 and the Medicare program, I mentioned that Medicare provides coverage for only about 1 or 2 percent of persons with AIDS. You recall from our discussion in December, the main reason for this is that there is a two-year waiting period in order to qualify as a disabled person for Medicare coverage. Really if you read the fine print, it is a 29 month waiting period because you have to wait five months to get Social Security disability insurance, SSDI, which is like Social Security for the disabled, so it is a form of cash assistance to SSDI

beneficiaries. Then once you qualify for SSDI, that's when your two-year waiting period starts for Medicare eligibility. So all together you are talking about 29 months. So while an AIDS diagnosis would qualify you as disabled, you still have a long time before Medicare coverage would kick in.

Once you get Medicare coverage, you have reasonably good coverage for hospital and physician services, but Medicare does not cover prescription drugs except when you are a hospital inpatient, and it has very limited long-term care benefits, very limited nursing home benefits, home care, some hospice benefits.

In addition, the other thing to know about Medicare, to remember about it, is that it has fairly substantial deductibles and coinsurance; over a $600 deductible for hospital services; there is now a $100 deductible for physician services; 20 percent coinsurance for physician services. Physicians can bill on top of what Medicare pays. There is a Part B premium, about $30 a month now. And all of that, with the uncovered services, particular the prescription drugs, means that you could be covered by Medicare and still have quite substantial out-of-pocket spending.

COMMISSIONER GOLDMAN: If I may, I'm not sure really that is necessarily really practically true in the case of a person with AIDS or HIV infection, because the reality is that for any health care provider caring for somebody with AIDS or HIV infection, particularly in terms of long-term chronic issues, they are more than happy to take the 80 percent and go home and never bother to look to the patient for the additional 20 percent. They may have to go through some elaborate procedure by which they have to provide evidence that they have made some kind of modicum effort, like they called the person and the person told them that they couldn't afford it so they decided that it wouldn't be worth it to send them into bankruptcy. But the reality is that there isn't a home care -- for example, in terms of providing physician services, they are a lot happier getting the 80 percent of Medicare than whatever the local Medicaid may pay.

DR. DAVIS: Good. That's a good point. I should also mention that if you are poor and have an income below the poverty level, Medicaid is now mandated to pick up Medicare disabled and elderly beneficiaries, pay your physician Part B premium, pay your deductibles and

coinsurance. So for the poor disabled population covered by Medicare, the Medicaid program must now supplement.

The other point you are talking about is simply that a provider may decide to let the bad debt go and not make a serious effort to collect. On the hospital side, first of all, Medicare will pay the hospital for any bad debt that it incurs by not collecting that $600 deductible. So again, if the person can't pay, wouldn't qualify for Medicaid to supplement Medicare because their income is a little bit above poverty or they had some assets, then Medicare technically is supposed to pay its own bad debts. So that there is less pressure on the hospital to collect. And the point you are making I think is a very good one, that the physician may also really not make a serious effort to collect their 20 percent coinsurance. Technically under the law they are supposed to show a good faith effort, but as you say, that can be variously interpreted.

I even think with the new physician payment system coming in that ought to be changed, that the provider shouldn't be under pressure to collect the 20 percent. It goes back to the old system where they were afraid they would jack up their charges and then not really try to collect the

other. So I think those are very good points.

CHAIRMAN OSBORN: Tim Westmoreland. .

MR. WESTMORELAND: Don, if I could respond for a moment though, I think first, if you are proposing Medicare as an alternative for financing much larger populations of the HIV population, you are not going to find the same willingness to accept the 80 percent and let it go. I mean, people can do it when it is 1 or 2 percent of the HIV population. They are not going to be able to do it the other way. And I think, finally, systemically we have got to also keep in mind that we are looking at this system for what the system can afford. And yes, the patient is better off if nobody makes the effort to collect the other 20 percent, but some doctor and some hospital someplace are expected to eat that cost along the way. And I think we need to keep in mind that the system has to stay solvent for the rest of the population too.

DR. DAVIS: I'd like to turn then to Medicaid.

MS. HARLOW: I would like to give you an overview of the Medicaid program. The purpose of the Medicaid program is to provide health insurance to low-income and disabled individuals. It is as currently the most important source of

health care financing for individuals with AIDS. In 1990, it is estimated that Medicaid provided health insurance coverage for 40 percent of the individuals with AIDS and approximately 47,000 individuals. And this figure includes coverage to approximately 90 percent of all children with AIDS.

By the end of 1991 this figure of 47,000 is expected to increase to about 56,000. And this sharp increase may partially be explained by the increasing number of Hispanic and Black individuals with the disease. They tend to be at higher risk of being low income.

Medicaid is a combined federal/state program under which the federal government will match state funding. In order to receive these federal funds, the states must meet specific federal requirements, but once they have met these requirements they have a fair degree of autonomy in setting the Medicaid eligibility criteria and in determining the benefits that will be covered. States do have the option of providing additional health care coverage using state-only funds.

In fiscal year 1990, Medicaid expenditures on AIDS and HIV related health care benefits totaled $1.3 million. This was split between the federal government and state

government; $670 million came from federal funds and $630 million came from state funds.

Because states do have autonomy in designing their Medicaid programs they do vary considerably in terms of the eligibility criteria set, and also in terms of the benefits. There are, however, three main programs under Medicaid under which individuals with AIDS or HIV infection may qualify. The first is AFDC, or Aid to Families with Dependent Children; the second is SSI, or Supplemental Security Income; and the third is the medically needy program. Each has differing eligibility criteria which also differ by state.

AFDC is a cash assistance program under which an individual will also have access to Medicaid. It is set up for women and children and has the least strict eligibility requirements of all the Medicaid categories. Essentially, women and children must only meet the income, or they must only have a sufficiently low income to be eligible. In 1990, the average income eligibility level was 88 percent of the federal poverty level. This would mean that an individual would have to earn approximately less than $500 a month, or $6,000 a year.

As mentioned earlier, these income eligibility

levels do vary by state, and in some they are extremely low. In 1988, the average income eligibility level in Alabama was 37 percent of the federal poverty level. In 1990 dollars this would be $210 a month or $2,500 a year.

SSI is also a cash assistance program under which Medicaid coverage is provided to the disabled. For an individual with AIDS to be eligible for SSI, they would have to show that they were unable to work and that they had a clinical diagnosis of AIDS. Additionally, they would have to have income an asset levels below the state eligibility criteria.

In 1990, the average income eligibility level for SSI was 191 percent of the federal poverty level, or approximately $13,000 a year. Additionally, an individual would have to have less than $2,000 worth of assets, not including a house or a car. The medically needy category is a state-only category, which basically means it is funded strictly from state funds. Although it is difficult to estimate, it is thought that 50 percent of individuals with AIDS are covered by Medicaid under this category. However, only 35 states and the District of Columbia have a medically needy category. Eligibility into this category is based on

accountable income, or an income after medical expenses. In 1990, the average income eligibility level across states was 68 percent of the federal poverty level, or approximately $4,600 a year.

Overall, many poor and near-poor individuals with AIDS do not have Medicaid coverage because of the stringent income and asset restrictions, and also because of the requirement of a clinical diagnosis of AIDS. The clinical diagnosis is based on the CDC definition and does not include earlier stages in the progression of the disease, particularly with regard to HIV infection. This prevents many individuals with AIDS and HIV infection from receiving Medicaid coverage, and as a result, many have problems getting costly early intervention treatments.

It is estimated that Medicaid only covers 25 percent of the medical care costs incurred by an individual with AIDS, and this is largely explained by the problem of Medicaid coverage only being provided in the latter stages of the disease.

Ten states have taken steps to extend Medicaid coverage by applying for home and community-based waivers under Section 2176 of the 1981 Omnibus Reconciliation Act.

Under these waivers, eligibility criteria for Medicaid are more lenient. Once an individual does have Medicaid coverage, he or she is basically covered for most ambulatory and inpatient services. There are, however, limits, but often an individual will still be covered for limited services under the grounds that the service is medically necessary.

One problem with the benefit is that the provision of prescription drugs by different states is optional. All states cover the main drugs needed under the categorical programs AFDC and SSI. But currently 14 states do not provide prescription drugs under the Medically Needy category.

A second problem with the Medicaid coverage is the low provider reimbursement rates. This has even reached a point where there is increasing concern for recipients having difficulty finding a primary care provider. And secondly, the low reimbursement rates are a financial burden on hospitals.

A final issue which I would like to mention with regard to the Medicaid program which is a concern is the disproportionate share or higher concentration of populations

with an AIDS or HIV infection in specific states, and this is of particular concern at a time when there are state deficits and fiscal pressures.

COMMISSIONER AHRENS: I want to go back to the part about the medically needy that is sort of incorporated into the MA, the medical assistance. I'm a little puzzled as to why we put that in that category, because the funding is different, and where MA is a national program and every state has something, every state doesn't have -- as you mentioned, only 35 have some sort of general assistance medical care. It seems to me the issues are different in terms of how we address them and whether that shouldn't be almost pulled out and put in sort of a separate area. It is totally state/local funded, it is totally optional in terms of the states, and --

DR. DAVIS: When we use the phrase "medically needy" we are not talking about general assistance, so we are talking about that part of Medicaid that is federal/state matched assistance. But to qualify as medically needy, you have to fall within the categorical requirements of AFDC or SSI that have an income that is within 133 percent of the AFDC income eligibility level after medical expenses. So

again, Medicaid, it is hard to explain it simply, but we are not talking about general assistance or state-only programs; we are talking about a category within federal/state Medicaid funding.

COMMISSIONER AHRENS: Well then in the report that we received there was no mention of this population that is eligible for what I call GAMC, which because of the nature of the population would I think in most instances incorporate very, very many of the individuals that would be HIV infected. And it is a very expansive program in many states and would be very important for the population we are talking about, and I'm wondering how we can get at that population and that program as we design our financing issues.

DR. DAVIS: Right. There is a very brief treatment of it on page 29 of the report of the state-only funds going under general assistance or others going into the care of persons with HIV and AIDS. But, obviously, as there has been inadequate health insurance coverage, inadequate coverage under Medicare and Medicaid, these states have had high concentrations of populations and local governments have stepped in with their own funding to provide some care. We have not tried to do a very thorough discussion of that, or

other sources such as VA that are also available to provide some support for services.

As you think about any of the policy options that are before you, there are kind of two implications as we get to those. First, is expand insurance coverage, whether it is under Medicare or Medicaid, national health insurance, private insurance. It will reduce the financial burden on state-only programs and VA or others that are providing services without compensation.

The other option though would be simply to provide federal funds under a direct categorical program like the Ryan White Program Act that would give money to the states to continue to directly fund providers who are providing those services. So, you know, I think we have not really been able to kind of go through a lot of the state-only support for care, but it is one that you should keep in mind that is both there as a current practice and think about it and how it would be affected under different policy options.

COMMISSIONER AHRENS: But I want to pursue this just a minute. Do we have any sense of the total amounts in terms of these general assistance-type programs that states and local units are putting into this effort through that

kind of program? I would suspect it is very considerable and ought to be something that we look at, either as a trade-off or how we in a sense reinforce that. Because, as I say, it deals mostly with single individuals, mostly males, very poor, and address the population that I think we clearly see is going to be emerging.

DR. DAVIS: Right. The one source that we have, the Intergovernmental Health Project, has been putting out some reports on state-only funding. In 1989, I think we mention in our report that about 65 million was spent by states for the care of persons. They are spending a lot more for testing, counseling, other types of preventive efforts. About 26 percent of that goes for inpatient care, 14 percent for outpatient area, about 11 percent for AZT case management services. But since that study, there have also been some new state initiatives, for example, to buy many people into what is called COBRA coverage, or keep their employer coverage going. So they are, as we understand it, currently doing a new survey of the states to get a better fix on what the current outlays are for care.

COMMISSIONER AHRENS: And do you have any data on local government's share? Most of these programs are state

and local, not just state dollars. So do you have any sense of what the level --

DR. DAVIS: No, I don't have separate figures on local government only. Because when you talk about public hospitals at the local level and the kind of bad debt, you know, it is an indirect subsidy at the local government level that is quite substantial I'm sure.

COMMISSIONER AHRENS: The National Association of Counties's figure is 8 billion in terms of county contributions to indigent health care, and I don't know how that would shake out in terms of what goes for AIDS.

DR. DAVIS: Certainly that is roughly consistent with figures that I have heard of six to eight billion dollars nationwide of uncompensated care. It is not just public hospitals, but I'm sure they do the bulk of that. So certainly if you are talking about all indigent, not just persons with AIDS but people without health insurance coverage, total estimates are on that order nationwide, and most of that, as you say, picked up by local government.

CHAIRMAN OSBORN: Harlon, and then Eunice.

COMMISSIONER DALTON: My question goes to the conversation that I think Don Goldman and Tim Westmoreland

were chomping at the bit to have with respect to whether it makes sense as a fall-back from universal health insurance to build on Medicare by essentially eliminating the waiting period -- I mean, all the things you sort of talk about in your report -- having Medicaid pick up coinsurance, et cetera, or build on Medicaid or some other option.

Each of you has said in your separate commentary that the Medicaid reimbursement figures are quite low -- I gather from the full report $7 for outpatient visits for example -- that the Medicare reimbursement rates are I gather sufficiently high so that physicians are willing to survive on 80 percent.

Can you give us a sense of what the comparative reimbursement figures are for Medicare and Medicaid for the same let's say inpatient procedure?

DR. DAVIS: I'm a little more comfortable with the figures for physician service,s but Medicare pays about 80 percent of kind of full charges or what a private insurer might pay that paid full charges. So Medicare about 20 percent below.

Medicaid in a new study of the Physician Payment Review Commission runs about 69 percent of the Medicare

level. So notching that down another 30 percent would get you what Medicaid does with regard to physician services. I'm not as familiar about the hospital inpatient Medicaid and Medicare rates, but I think they are roughly that order of magnitude discount from full charges of hospitals.

COMMISSIONER DIAZ: I just needed a point of clarification on something that you said, Jennifer. In terms of 40 percent -- your chart says 40 percent of the individuals with AIDS are covered by Medicaid. Then you said that Medicaid was only providing for 25 percent of their total needs.

MS. HARLOW: The cost per person, of the full cost that a person would incur over the progression of the disease.

COMMISSIONER DIAZ: It is only providing for 25 percent although 40 percent are --

DR. DAVIS: But I think what we are talking about is of the total AIDS care bill. So if we are talking about eight billion a year, 25 percent of that is paid by Medicaid. If they were paying full cost of all of the care at the right rates, they would be paying 40 percent. So I think that's the point we are trying to get across there, not that they

are only paying a fourth of the bill, sort of discounting or getting the care late. But again, all of this is pretty soft.

COMMISSIONER DIAZ: And my other question is on the pie chart that shows the 29 percent uninsured, approximately 29 percent, do you have any feeling for how many of those 29 percent are paying out of pocket? In other words, are uninsured but paying out of pocket versus those that become a total burden on --

DR. DAVIS: Again, we weren't able to get anything on what we characterize as self-pay versus no pay, or reduced pay, so I can't even take a stab at that one in terms of being able to estimate how much of their care really shows up as a burden on local hospitals, public clinics, as opposed to actually being paid.

I'd like to turn to some of the other problems besides just strictly financing problems that we feel lead to barriers to early intervention and appropriate care of persons with HIV and AIDS, and also how this patchwork system of financing affects those providers that do provide services.

COMMISSIONER ROGERS: Dr. Davis, a suggestion.

DR. DAVIS: Yes.

COMMISSIONER ROGERS: One, permit me to say you have put together some beautiful material for us and just hearing the questions, clearly all the Commissioners have read it. I would paint with a fairly broad brush so that Commissioners can ask those questions, because I think everybody has read that splendid document you put before us.

DR. BEYRER: I'm going to talk initially about barriers to early intervention, I think just to paint broadly and begin, I think there is a general medical consensus that early intervention is something we really should be heading for, preventive care for people with HIV infection before they get sick, and preventive care and treatment for people once they do have a diagnosis of AIDS.

Key points in early intervention are that it can certainly help curb the spread of the disease through education, through counseling, through offering contraceptive services to women with HIV infection who would be at risk for having children, through encouragement of treatment programs for addicts. There is good evidence that addicts, IV drug users, who get into early intervention do better in terms of getting off drug use.

Early intervention has been shown to prolong life expectancy. This is especially true for immuno compromised people who are progressing in the disease. It can reduce the incidence of serious illnesses requiring expensive hospitalization. And I think if there is any key point here, that's what I would underline in terms of health care financing, that we have really focused on inpatient care, which is costly, and early intervention can really help shift to outpatient care. And the other point would be increased ability of people with AIDS or HIV infection to work longer due to improved health from the beneficial effects of early intervention.

But obviously there are some very real problems with early intervention, and the most clear evidence for this is the fact that still the most common initial presentation of HIV infection is full blown AIDS in the emergency room, and that is something we really have to work to change. There are a number of barriers that bring this situation around -- patient-centered barriers arising from still the very negative connotations of testing, the negative implications of being found to be HIV infected, the insurance underwriting that we have been talking about.

Counseling and lack of counseling for testing, which, of course, is the first step to getting into early intervention, is still a problem in the small insurance market. Larger insurance companies and most of the government health projects have counseling, pre and post-test counseling, for HIV infection. The small insurance companies don't necessarily need to do that, or to inform people, incidentally, that they have tested positive and that's why they are being denied insurance or employment.

In terms of special populations, IV drug abusers traditionally have been the most difficult group to reach with any kind of health intervention, and early intervention in HIV infection fits under that category. Vlahov, who has probably looked at this more closely than anybody, has found that to get addicts into early intervention you need appropriate locations, you need to ensure confidentiality, you need to have good follow-up and referral systems. And what we are talking about in terms of inner city public health clinics, obviously there are great gaps between what addicts are willing to accept and what is offered.

In terms of women, of course, women with HIV infection are typically poorer than men. They still have a

shorter life expectancy, and this may be due to difficulties of early intervention. And we still have problems with the CDC definition. There are some women's groups and activist groups, women with AIDS, who feel that a number of infections in HIV infected women are not included in the CDC definition, so by definition they get into treatment later.

In terms of physician or provider centered barriers, there really are three crucial ones. One is simply the lack of primary care physicians in inner city areas. The second, which Jennifer has alluded to, is the fact that 40 percent of people with HIV are on Medicaid and Medicaid reimbursement is very low, so this remains a barrier to early intervention.

The third, unfortunately, is the unwillingness of some providers to serve the HIV infected population. There is good evidence from Maryland to show that minority and IV drug using people with AIDS get less care and less aggressive care.

The last two points I would like to make are that monitoring and treatment, as we have seen, for early intervention, our cost figure is about 5,000 a year. For that segment, however many people there are, who are

uninsured and self-paying, this may well be prohibitive. If you can't afford health insurance you are unlikely to be able to afford the 5,000 a year for early intervention.

And then lastly, that the orphan drug monopoly status, which I will describe in a little more detail, has inflated the price of the two key drugs in early intervention -- AZT and aerosolized pentamidine -- and this has really been a barrier to early intervention.

So just quickly, the Orphan Drug Act. The Orphan Drug Act of 1983 was basically established to encourage research on drugs which were likely to have limited profits in relation to research costs, and it was extended in 1985, the definition, to include drugs for which there was a target population of under 200,000. It provides financial incentives, tax breaks, and most importantly, a seven year exclusivity on marketing, so that you have monopoly price fixing of these drugs. AZT was granted orphan drug status because its initial indication was for full blown AIDS, and at that time, of course, there were not 200,000 people with full blown AIDS. We still don't necessarily know if there are, or hopefully will not be, 200,000 people. But at this point AZT is now being used for early intervention, and so

the actual number of people who can benefit from this therapy if it were affordable is probably closer to half a million.

Pentamidine was also granted orphan drug status. When it was granted orphan drug status its price immediately jumped up 400 percent under the monopoly marketing.

And the last point I would like to make is that any other anti-retroviral, such as DDI or DDC, which is likely to be approved, under the current orphan drug law would probably be priced again under monopoly and would be roughly in the same cost bracket as AZT -- $2,700 to $7,000 a year.

The last point I would like to make about inefficiency in current care goes back to the problem of inpatient versus outpatient care and the financial inefficiency involved in the current system. There is good evidence to show that there are better ways to do things. In the San Francisco area, it was found that there were lower AIDS treatment costs, and our assumption and the assumption of the people who did that work is that it is because of the strong emphasis on outpatient, home-based care and on case management.

There may also be an effect of inefficiency due to unfamiliarity with newer and lower cost treatment regimens,

and this is especially a problem in the lower HIV prevalence areas outside of the major cities. And lastly, there is some evidence in terms of PCP prophylaxis that we could be doing much more efficient work in terms of preventing PCP. It is essentially at this point a preventable disease, and as I said at the beginning, it is still the most common presentation.

CHAIRMAN OSBORN: Thank you. Questions? Don Goldman.

COMMISSIONER GOLDMAN: Did you say that in a majority of the cases the first diagnosis of HIV disease was the presentation is full blown AIDS?

DR. BEYRER: It is not necessarily the majority, but in terms of the presentations it is the most common. It is the most common single of the different presentations of HIV, is PCP.

COMMISSIONER GOLDMAN: My other question is to what -- does not the Orphan Drug Act Amendments bill which was passed by Congress last term and pocket vetoed by President Bush solve many of the problems regarding AZT, or doesn't it? I mean, does it address it or doesn't it?

DR. BEYRER: It would have solved -- you are quite

right -- some of the issues that we have brought up here, and that's part of the reason why we wanted to bring this up again, because there is real potential, it would seem. There is legislative agreement that it could be passed.

COMMISSIONER GOLDMAN: And I don't know whether you are familiar with it. The seven year period of exclusivity under the Orphan Drug Act, does that mean that let's say a drug like DDI in order to be approved would have to prove superiority over AZT in order for DDI to be approved for that seven year period?

DR. BEYRER: No. Each drug is given orphan drug status based on the criteria of the act. So at this point neither DDI nor DDC has to be proven to be superior to AZT to be approved, because there are a number of people who are intolerant to AZT.

COMMISSIONER GOLDMAN: Okay. But as a drug, other than for those that were intolerant to AZT, they would have to prove superiority over AZT in order to be approved?

DR. BEYRER: To approve a new drug you don't need to have superiority, you have to just prove effectiveness. You know, there are 40 drugs licensed for hypertension. You don't necessarily have to be better than the competition.

COMMISSIONER GOLDMAN: But I'm talking about with the orphan drugs. I understand that, you don't have to approve it for approval FDA status-wise, but I'm am saying once you have given the seven year marketing exclusivity, isn't that an exclusivity on marketing for that particular -- Tim, did you want --

MR. WESTMORELAND: If I could. It is exclusivity for the marketing of that substance, it's not exclusivity for the marketing of something for that condition. It is exclusivity for marketing aerosolized pentamidine so that a generic drug manufacturer or another name brand manufacturer can't come in.

COMMISSIONER GOLDMAN: But how does that expand beyond -- if a company has a patent on AZT, presumably that would last for longer than the exclusivity under the Orphan Drug Act?

MR. WESTMORELAND: That's exactly what I was going to jump in to say for the question you asked -- while I was out of the room, I'm sorry -- about the veto of the Orphan Drug Act Amendments and whether it would have solved the problem.

I think while I staffed that work on that

legislation and certainly support it, I don't think we should oversell what the amendments could have done. AZT under current law enjoys a patent which lasts at least 17 years, and I think probably 24 under the patent term restoration law. So AZT's monopoly status would have been unaffected.

DDI and DDC also will have patents coming, so unless the patents are subsequently invalidated, the orphan drug status for those drugs is essentially irrelevant, because there is a marketing monopoly that derives from a patent law that is, as you say, longer than the orphan drug status. It would have helped significantly I think with aerosolized pentamidine.

DR. DAVIS: Just a final quick point we want to make is about how it affects the providers in terms of the geographic concentration of persons with AIDS and the problems with either self-pay or no pay.

DR. CHAULK: I will try and be somewhat brief with this. Basically there seem to be two main problems with the burden on providers, and that is namely the distribution geographically of the cases of HIV and AIDS, as well as the type of people that present with the problem. As has already been mentioned, about five states contain roughly 60 percent

of all the AIDS cases at this time, and within those states we can localize those to mainly urban areas, and increasingly that will spread specifically to the inner city areas as well.

In terms of the population, we are talking in many cases, at least at the AIDS state, of being uninsured, or certainly underinsured, and so we have a major concentration with a lack of financing to care for these people. As a result, the typical site for care is in the emergency room and typically that emergency room is in a teaching or public hospital. It may also be in a community health center or community clinic which is staffed by volunteers.

Because the care may occur in the emergency room, clearly there is a question here of continuity of care and quality of care, not because emergency room physicians provide lower quality of care but that the focus is on the immediate problem and not the whole patient's constellation of problems, particularly with a chronic disease like AIDS. As has already been mentioned, in many cases physicians even in the emergency room may be reluctant to treat patients with HIV or AIDS, particularly if they resemble IV drug users or may be of minority status. In some cases care may be refused

-- that is not easily documented -- and in many cases where the patient is being covered by Medicaid in the outpatient setting, again it has been suggested that that person is somewhat less likely to be received with open arms than if they have private insurance.

In addition to this burden on providers, I guess this is a point where we can at least make some mention of the Ryan White Act, which attempts to address this problem but doesn't do it quite as fully as we would like it to do. The Ryan White Act was passed in 1991 in response to the case of Ryan White in Indiana, who was a hemophiliac who acquired HIV infection and died. The bill basically authorized $1.1 billion to be spent over two years. That was then reduced to 875, down to 351, and I think the last appropriation after Gramm-Rudman was somewhere around 230 or $240 million for fiscal year 1991.

It has several titles to it. It provides categorical grants to cities for a variety of health services, and at the present time there are 16 cities that qualify for this due to a case load of over 2,000 cases within those cities, and then Jersey City, New Jersey had an incidence rate of .0025, which is another way to qualify for

this. So there were two ways to do that. It is anticipated, I guess, that maybe four or five more cities within the next year will then qualify under this as well.

In addition, Title III is one that we are concerned with in the sense that that focuses on preventive care and deals with issues of providing testing and counseling, some outpatient services, as well as referral patterns, and I think that's in addition to the main treatment that we find for the relief under Title I. We would like to see more emphasis placed on Title III in the future. And then Title IV deals with some demonstration projects that focus on pediatric AIDS cases.

CHAIRMAN OSBORN: Charles.

COMMISSIONER KONIGSBERG: The voice from middle America again. The Ryan White Act, at least at this juncture, in our state is causing us a great deal of difficulty, and I guess later in the day I'm assuming, June, that we'll start discussing various options. There is no doubt that the concept behind the Ryan White bill is a valid one, but what is happening to states that are outside the epicenters -- which is actually most of us -- is that what's mandated to do, which is the early intervention centers, the

money falls far short, and in order to keep most of the federal money flowing we are stuck with having to do it.

This now places me in a very uncomfortable position of having to take the issue to our governor and our state legislature at a time when there are many pressures on health care for issues that affect many more people than AIDS in our state. I don't know how all of this is going to play out, and we are by no means the only state. And Don and I were having breakfast this morning. I think he correctly characterized the Ryan White bill is its main purpose -- he used the word "ethics" -- but I think its main purpose is financial relief for large cities, and I think there is something to that.

So as we go through those options this afternoon we really need to look at how this act affects most of the United States and what recommendations we might have to fix that.

COMMISSIONER GOLDMAN: I just wanted to know, it looks to me, in terms of a chart, that we are beginning in the next step to begin to go on to the various different options, and I was just wondering how you intended to go through them one by one, because, I mean, there are some

generic issues that deal with all of them and some general policy issues that I'd like to have the opportunity to discuss in terms of looking at it on an overall basis rather than focus on the seven or eight policy options that you are referring to on a stand-alone basis without relating them to each other. Again, I don't want to interfere with what you are doing, but I have some concern about how we are going to end up discussing them.

DR. DAVIS: We will be responsive to however you want to do this. It is now about 10:10. I think we had thought that what we have done so far would take us up to 10:30, so from my point of view we have got about 20 minutes, and what we had planned to do is to have some more general discussion before we get into specific options.

We had planned then after a break to kind of go through each of the options, be sure that we understand what the major strengths and weaknesses, again with a fair amount of back and forth as Commissioners are interested, and then after you have thought it over over lunch to really have a more general discussion but drawing particularly on the views of several experts who have been brought in to react to it.

So we're quite willing to proceed anyway you want,

but maybe after we get Ms. Ahrens concerns we could spend 15 minutes or so with some general discussion before getting to specific options.

COMMISSIONER AHRENS: My concerns I think I'll hold until we get into that discussion. I think they would be more relevant as we move through.

CHAIRMAN OSBORN: Okay.

DR. DAVIS: Well then before just starting through the options maybe it would be good to open it up to some general discussion. What you have seen laid out for you are some incremental policy options that would focus on expansion of Medicaid, would try to keep people's employer-provided private insurance in force longer, those that would try to cover people under Medicare, either by letting them buy themselves in during that two-year waiting period or just eliminating the two-year waiting period, reforms of the market for private health insurance that might make such coverage more affordable, more accessible, more available to people. But also looking at some specific policies that might be targeted on expansions or improvements in the Ryan White Act, dealing specifically with the price of drugs given the patent situation, given the orphan drug protection, what

could you do to try to make those drugs available at a lower cost. And then finally to talk about somewhat more comprehensive approaches in terms of a universal approach to health financing for the entire U.S. population.

As we have tried to put this information together, we have obviously had to focus specifically on the HIV/AIDS population. That is not to say we would recommend an HIV/AIDS only approach to improving health financing. We recognize there are a lot of people in this country, whether they are disabled or working, whatever, who do not have adequate health insurance coverage and we assume that our society would want to deal with all of those and not just specifically with the HIV/AIDS population. They might choose to do it in a phased way, in which case there might be a sequence. Whether it is the first group or the second group or the third group that comes in, I think it is useful for this Commission to know what the cost parameters are specifically for the HIV/AIDS population, how many people would be helped, what it would cost, but we are not really advocating at all a strategy that would focus only on this population group and ignore the needs of others in society. But I think it would be useful to get your views out on the

table before we turn to specific options.

CHAIRMAN OSBORN: Diane.

COMMISSIONER AHRENS: I really would like to reinforce that. I think whatever report this Commission comes out with has to come from a view that this is an absolutely essential thing for this country to do, to deal with the total population of this country that has no private or public health insurance and to sort of lend our voice to I think the chorus that is beginning to arise out there among all kinds of communities to say that we have got to deal with this. Because even if we do and could accomplish everything in this report, which I think we know we politically can't, it isn't going to do what we feel has to be done, at least that's my sense of it, and whatever we come out with as a recommendation I think needs to have a prologue or introduction or something that deals with that comprehensive nature and talks about all of the indigent or noninsured in this country rather than just singling out one population -- I think it is terribly important -- and come at it in the way that you have described, which I think is maybe more politically doable, that we carve off segments of that population and go at it in this way.

Having said that, we can then move to some incremental approaches, but I think that is terribly important.

COMMISSIONER ROGERS: Before we move, that's such a ringing statement from our Commissioner I want to buy on. I think that is a very important statement you have made, Diane, and I categorically agree as one Commissioner and telegraph my prejudices.

Karen, it prompts me to ask a kind of a follow-up question. I know you have just come from a discussion of this, and some of the literature I have seen suggests, particularly in terms of the incremental bit, that people might buy some things from column A, some from column B, some from column C in terms of moving toward that kind of entitlement for those who are not insured.

Do you have any feel for -- I think I'm reflecting what Diane has said -- in terms of the political climate how do we move toward that goal in ways that in terms of all the input to you might be most pragmatically approachable right now?

DR. DAVIS: Well I agree with Ms. Ahrens' observation that there is just a lot more concern, a lot more

interest about the need for action in a comprehensive approach to assuring universal health insurance coverage. It is coming from the general public, but Congressmen are feeling that from discussions with their constituents. Certainly other actors like business, labor, are very concerned about this issue.

There are concrete legislative proposals now starting to be put on the table, others that are in the development that will be announced very shortly. The Ways and Means Committee has been having hearings last week and this week on approaches to universal health insurance coverage. So there is far more interest than I have seen at any time in the last 10 years toward the need to do something.

On the other hand, I also get a sense that the judgment is it may take four, six, ten years even to get such a comprehensive approach in place. And if we look at our very first chart and just see the rise in the number of cases, I don't think any of us feel very comfortable about not taking some steps that would begin to deal with the most serious problems at least in a shorter time frame than a decade.

In terms of approaches that are being tossed out there, I would characterize them as basically three types. There is a type that tries to expand private insurance, either voluntarily or by requiring employers to offer it, pay for it. So it is private insurance, it is employment-based, it is trying to reform the market to eliminate some of these underwriting practices so that everybody can get coverage, but it may still be at a very high premium. So it is only if the employer is contributing significantly and required to contribute significantly to it that you are going to see much change.

The second type of proposal I think is best represented by the Pepper Commission report, and I think that several leaders in the Senate will be coming forward with a legislative proposal in early May that will take up the shape along that of the Pepper Commission. I call it a mixed public/private approach to achieving universal coverage. It would require employers to provide some coverage to their workers but giving them the option of either buying into a public plan like Medicare or buying private insurance from a group insurance and then filling in with a new public program that would probably even replace Medicaid, that would cover

everybody else. So everybody would get covered under something like Medicare or under a large group insurance plan and employers would be contributing.

The third type of approach -- and there are two bills already -- well, three bills already in the hopper -- Congressman Marty Russo from Illinois has an -- well, this third approach is what I call the all-public, a single public plan that covers everybody. Congressman Russo's so's bill, many would call it kind of a Canadian-type plan. It is a single public plan, comprehensive benefits, no cost sharing, everybody is covered, financed with a mix of taxes.

Congressman Pete stark, who chairs the Health Subcommittee of the Ways and Means Committee, Congressman Sam Gibbons on that committee, both have bills that are the Medicare-for-everybody approach. So under those plans every citizen, every resident of the United States would be covered under Medicare. So there would be no two-year waiting period, not only for the elderly or disabled but for the non-elderly. It would cover everyone. So their idea is simply it is a good program, get everybody in it. Employers would contribute to it through a payroll tax or a premium that they would pay into Medicare, but anybody is

automatically covered by Medicare. Your employer contributes, there are some other sources of revenue, income related premiums, general tax revenues that go into supporting it. The Gibbons and the Stark bill differ a little bit on financing of where the money comes from.

So those are the kind of three approaches that are being talked about and I think getting serious attention in terms of when leaders in the House and Senate have a bill in the hopper with their name on it and there are hearings, that's serious attention.

On the other hand, I think there is a little bit of caution about how quickly anything like that will move.

COMMISSIONER ROGERS: I guess I want to push you a little bit farther, Dr. Davis, because it seems to me our 40 year history is each quite doctrinaire approach, like the number three you mentioned, has fallen on its face, and I think part of my question was what are your political instincts in terms of what kind of compromise of the different competing ones might move us really toward covering those uninsured, might really move us towards a universal thing?

I asked that in that I so agree with Diane Ahrens

that everything we look at in terms of AIDS, it falls on its face because so many people can't get the primary care services. That all of our different programs flounder, in reading the different material before us, it is very impressive that that's the Achilles' heel, that we have got to cover those groups or all other things fail for us. So I am sure one of the things we are going to be focusing on is how can we go at this in a non-doctrinaire way that might achieve that coverage we all seek for those who are having such a tough time getting health care.

And I doubt that it is going to be just a single approach. Are there packages we could put together that people would buy?

DR. DAVIS: Well, you have certainly been around this process a long time, as I can tell from your comments, and I think my views are very much like yours. Those on the one hand that would just give incentives to employers to offer coverage, would make some reforms in the private insurance, are unlikely to make a big dent in the problem because so many of those people are uninsured because they can't afford it. The employer is not going to be contributing even if it is more accessible and available.

On the other hand, the all-public plans, whatever the strong points you can say about -- they are simple, you are guaranteed to be in one plan forever, you don't have to worry about changing -- they have got a lot of advantages.

On the other hand, when you really look at the price tag and what it means in terms of the taxes that would have to be raised by the federal government to pursue them, in the context of a large budget deficit already, strains on existing programs, it is hard to see those even the six to ten year horizon. So I think that my guess would be something more toward that middle mixed public/private approach, something like the Pepper Commission plan. Something like giving employers the option of covering their workers under Medicare or under private insurance is somewhere like a middle ground. But as you think about that option and you think about the population of concern to this Commission, I think then to keep in mind that Medicare's benefit package is not ideally designed for the care of persons with HIV/AIDS, and maybe to express some of those concerns would be a useful contribution as well.

CHAIRMAN OSBORN: Harlon, and then Don.

COMMISSIONER DALTON: Well, I think my question is

simply David's again.

In going through the different options or combinations of options, I guess what I'd like to know is which ones do you think in fact would speed up the timetable of four or six or ten years toward some form of universal coverage? That is to say we obviously have some choices here in terms of our fall-back position. What is your best sense about what might in fact advance universal coverage? A specific plan, a plan that was focused around chronic and fatal illnesses as against other illnesses, expanding Medicare as against expanding Medicaid, what particular kind of fall-back not only would speak in the short run to the concerns of the people that we have been called together to speak to and for, but also would push politically in the direction of universal coverage?

DR. DAVIS: My response is a little more of a analytic response than a political response. I'd also like to call on maybe Tim Westmoreland of others who have a little bit better sense of the politics of this issue.

If your long-run goal is to get everyone covered under either a Medicare program or under a good large employer group health insurance plan, then intermediate steps

would point toward more of a Medicare strategy, whether that is letting people buy in it, shortening the waiting period, or other kinds of things.

On the other hand, as we will get to those, those are more expensive options than more targeted narrow Medicaid options. They don't help as many people. They help the low income who are not now on Medicaid, but they cost less money.

On the other hand, politically -- and I'm sure Dr. Konigsberg is aware of that -- the states are feeling a lot of fiscal pressure from the expansions in Medicaid coverage for pregnant women and children and elderly and disabled, so that is also a political barrier to saying you could move forward with some additional Medicaid expansions for those with serious illnesses such as AIDS.

I don't want to put Tim on the spot, but I just feel a little uncomfortable telling you about the politics of this when there are others who know more.

MR. WESTMORELAND: I guess I would say that it depends on how much you want this Commission's recommendations to discuss the actual day-to-day workings of Gramm-Rudman type three, or the various jurisdictions of the committees, and how much the price tags are going to be and

what the difficulties are of raising revenue versus what some ideal solutions might be for putting together incremental steps towards national health insurance. I really think in that question you have got to decide which goal you want to try. Do you want something that the Congress could implement by the end of the 102nd as a recommendation for this Commission, or do you want something that will over the long run lead towards a national health insurance? Because I think those are necessarily the same things.

COMMISSIONER DALTON: Are you taking that you think they are probably incompatible or mutually exclusive?

MR. WESTMORELAND: I think that there are very few things that you will be able to implement by the end of the 102nd Congress that are ambitious, that the Gramm-Rudman system under current law makes it very difficult to make any of the expansions, either in Medicare or Medicaid or general public programs, and that the only kinds of programs you would be able to put together as a recommendation would be very incremental, and I doubt that they would make much difference towards national health insurance one way or the other. Not that I think they would be inconsistent. I just don't think they would lead very far.

And my concern -- and this sort of Cassandra concern I keep voicing in my own staff all this time - is yes, I understand that what we are all moving forward is a universal health system, but in the meanwhile, in those six to ten years we are going to lose half a million Americans because they don't have any access to the basic care that we could already provide to them. And so I'm always the person -- and I concede my prejudice frankly -- I'm always the person who is trying to find the incremental benefits that we could implement today, tomorrow, the next day to provide early intervention and PCP prophylaxis. But meanwhile there are other people who are trying to provide long-term health insurance. I don't think they are necessarily inconsistent, I just think they run on -- if you will excuse me -- parallel tracks.

COMMISSIONER GOLDMAN: You know what Tim said is correct, and while I agree with Diane wholeheartedly, the reality is if one takes into the time it is going to take to develop a consensus as to the nature and structure of a kind of plan of national health insurance, then we talk about the development of a consensus as to how that plan is going to be financed, and then we talk about the time it is going to take

to implement such a plan and actually put it into place.

In all likelihood, any person today ill with HIV disease is likely to be dead before such a plan is ever implemented, and I don't think that we could fulfill our responsibilities very well by saying that we ought to deal with that future plan, because that in reality may condemn, as I think Tim said, thousands of people to a premature and unnecessary demise.

At the same time, sort of cynically speaking -- and please, I'm suggesting exactly to the contrary -- but I suppose one could argue that the fastest way to get to some national health insurance plan is to do it over the backs of those hundreds of thousands of people who are dying, and it is their deaths and their suffering that will in fact lead this country to developing a national health insurance program, and I reject that alternative wholeheartedly from a personal perspective.

But I think we ought to acknowledge that to a certain extent all that we do incrementally may in fact cause some delay in that process by removing some of the pressures towards the development of a national health system, but that's a price that I think is necessary to pay.

One of the concerns that I have that I did want to discuss that is mentioned throughout the report is I have real concerns about the political realities of being able to get any kind of program through Congress which is limited to AIDS and HIV disease on a stand-alone basis. There are problems with it in terms of it is difficult to defend on moral and ethical grounds. It is a problem because if you talk about AIDS and HIV infection on an incremental basis and you are talking about doing it perhaps category by category, disease by disease, I don't know how you do it. AIDS ends up being perhaps one of the more expensive diseases, and therefore if you are going to do so incrementally, it probably ends up being one of the last ones to be included rather than the first.

Politically we have all seen the problems of AIDS and HIV infection even in terms of the context of the Americans with Disabilities Act, how difficult it was to get that passed and how even with the coalition that was developed the difficulties in keeping or avoiding exclusions for AIDS and HIV infection from the scope of that bill in many ways. And, of course, the recognition that, at least from my perspective active, the Ryan White bill passed, among

other reasons, not because it was an aid to persons with AIDS but because it was aid to impacted political jurisdictions. I mean, that was the political thesis of it. It was certainly an ethical base to a large extent, and I just think it is going to be very difficult to deal with some of these options.

Because I think the financing needs of HIV disease would probably best be met in terms of enlarging the base. I mean people with an expensive chronic disease end up being better off being lumped together with a whole bunch of other people who have less expensive chronic diseases or who have less expensive health care costs in total, so that the burden of that care can be broadened to as wide a base as possible. And I think that hopefully strategies can be developed to develop such larger bases for persons with AIDS and HIV disease, and once that it is done then I think that it is that kind of incremental approach that can best be done.

There are some other issues that we really have not dealt with that aren't dealt with in your paper, and I don't know whether they are intended to be. Number one is the problem of ERISA in terms of the special kinds of the exemptions from state insurance regulations that that is

causing. And you mention it peripherally, although I think we ought to deal with it, as to whether or not the definition of disabled which is now utilizing a CDC epidemiological definition, whether or not perhaps one of the things this Commission might do is urge the use of a more clinically based -- and I don't know whether or not you are talking about the Walter Reed staging criteria or some other criteria that might be used other than AIDS.

And the other thing that one of our reports mentioned and really wasn't covered is whether or not there is any way of providing financing in some way or some assistance for family-provided home health care services and the tremendous care that is being provided for by members of family for people with AIDS and HIV infection, and not necessarily they ought to get paid for it, but maybe there are some creative ways of finding some ways of assisting them or providing some support for them in some way, whether it even be by training or education. But it would seem to make a lot more sense that if a person is eligible for home health care services and they could be provided for by commercial paid people and instead they are provided for by members of their families, that at least those members of the families

ought to be able to be provided support services in some way, particularly if those support services would be a lot less costly than the services that would otherwise be eligible and paid for.

CHAIRMAN OSBORN: Let me suggest some of this is moving into areas that we will be spending the rest of the morning on. I know Charley and Diane both had indicated that they wanted to bring something up. Would that be okay with you, Don, if we don't, because otherwise we are a little bit into what we had scheduled as a break, and otherwise we may end up with a rather uneven time distribution when we could all be a little fresher.

DR. DAVIS: But I think that's good. It is putting some more options on the table.

CHAIRMAN OSBORN: Yes, I'm glad to have the brought up in order to think about. But if that is all right with you, Don, Charley and Diane and then we will take a break.

COMMISSIONER KONIGSBERG: Yes, and I will try to keep the comments fairly general.

It strikes me, just sitting here thinking about it a little bit, that we have got two major broad agendas I think as a Commission in terms of recommendations. One is

prevention, which we are not dealing with today, but in that one, and picking up on some comments that Don DesJarlais had made in the past, there are some controversial items that we can get into, but the fact is we can probably craft some recommendations there.

The tough one is the second one, which is the financing of the care, which actually is more than the financing, it is the system of care. And I actually took the time to read this entire paper. That plus the others took a fair chunk of the weekend. But I hope we'll go through this really point by point because there are many, many important points in there.

One of the points that was made in this paper, as I recall, was looking at AIDS care where it is done well -- and it is done well in some areas -- as a model for how the rest of health care ought to be delivered. And to me that's a theme we might ought to be able to pick up on in terms of making some long-term recommendations.

We have got some really tough work to do, and in listening to what Tim says and what Karen is saying, it seems to me we have got to try to come up with some recommendations that provide some immediate relief, but somehow we have also

got to make some long-term recommendations and do it in a way that doesn't get the two in each other's way. I don't know how we do that, but that's going to be difficult. But in order to do it, we have got to really work. I mean, we have got to spend the day going through this, and I know we won't solve it today. But in case anybody doesn't know it, and I'm sure we all do, this is tough work.

CHAIRMAN OSBORN: Diane, and then Harlon.

COMMISSIONER AHRENS: As one of the two politicians on this good body, I want to go to politics for a minute.

My friend says "elected politicians."

I want to talk about taxes, and maybe Tim would contribute to this for just a minute, and that is what is palatable. If we put our thrust with the Medicaid issues, I can see the opposition being absolutely tremendous, and that's because of where state budgets are. Gramm-Rudman notwithstanding, state budgets, especially in the states where this would be disproportionate. You have got New York, you have got California, you have got Texas, you have got Florida, and the runaway engine in state budgets right now is medical assistance. States are not looking to expand it.

In fact, in my state, and it has perhaps one of the

most generous of any of the states, they have sort of shoved medical assistance aside just a bit and they are saying, you know, we got a bigger problem here, we are going to find a way to cover all of those who aren't covered. And that's where the motion, even though it is going to cost a lot of money. But the incremental approach has sort of been, although we do it, is not where at least my state is. But I think for these other states, there is going to be great pressure not to expand medical assistance.

Then we come to Medicare and spreading that cost across the FICA, sort of a little bit of an increase there, which is not maybe as -- except among -- I don't know whether the American Association of Retired Citizens would get on that and say we don't want to do that, and for what reason I don't know since the rest of us pay it -- but maybe that's a little more palatable, maybe that's a little more doable. I'm just sort of thinking out loud here and wondering what your thoughts are, politically.

DR. DAVIS: I think that's good sounding.

MR. WESTMORELAND: I should issue some sort of disclaimer here. I am not in many ways a health care financing person, and I am definitely not a tax person, so I

should start by saying those kinds of things.

I would also very much defer to Dr. Davis, who has been around this in much more intense ways than I ever have been. But I don't think that you should discard either the Medicaid or Medicare options because of political reasons off the top. Because one of the things that I think that has been most confounding for people who are working in health care finance over the years is that while the politicians in Washington over and over again say we can't countenance any tax increases to pay for national health insurance, the polls time and time again say it is one of the few things that Americans are willing to accept a tax increase for.

So while I can't very -- I can talk off the top of my head about some of the debates that have gone on in Medicaid and Medicare, I don't think you should discard them off the top for that, and I would defer to Dr. Davis in discussing some of the proposals that have been made and what their fate has been.

CHAIRMAN OSBORN: Harlon, the last word.

COMMISSIONER DALTON: I don't think that I have heard that much disagreement around the table, and so I just wanted to sort of summarize where I think we are in

agreement.

First off, that we are in favor of universal health care to the employed and the unemployed alike, not for ideological reasons but because without it all else fails with respect to AIDS treatment.

Secondly, that we can't wait for that wonderful day in which such universal health care is available and we must therefore take incremental steps. Third, that in choosing those incremental steps, wherever possible we should choose steps that are compatible with and do not retard movement toward universal health care. And then the fourth I think is how we sort of pitch those incremental steps, whether they are AIDS specific or include everybody. My sense is that we understand that there are dangers with each of those, and I want to suggest at least as one possibility that one in between focus might be on measures that speak to people with chronic diseases rather than solely with AIDS, but also rather than the entire universe of people who are sick.

COMMISSIONER ROGERS: I know we are breaking, but that's such an important statement I hope everybody heard that. That is a wonderful preamble, Harlon, into this section.

CHAIRMAN OSBORN: As a matter of fact, I hope you have got it written down.

With that, let's break with the understanding that it is to muse on what we have talked about and come back refreshed.

[Brief recess.]

CHAIRMAN OSBORN: Let's get started again. A couple of people will probably be in in just a minute, and we have valuable time and valuable people with us.

I think we said hello to most everybody, but now I get an official chance to say hi to Phil Lee. Welcome and thank you for being with us.

The next section is entitled "Discussion of Policy Options for Financing Services," and as was said just before we broke, the issue is about as tough and thorny as anything that faces us so we need to get to it.

Karen do you want to start off?

DR. DAVIS: I thought Mr. Dalton's comments just before we broke really set the stage very nicely for this part of it, kind of reminding ourselves that while our ultimate goal is universal health care for the employed and unemployed, that we can't wait for that, we need to take

incremental steps, and that these should be compatible and not stand in the way of movement toward universal health insurance. I thought those were very helpful comments and that perhaps what we ought to be thinking about is not really an AIDS or HIV specific approach, but at least a chronically ill or chronic disease approach. So again, while we will be saying AIDS/HIV and giving you impact and cost numbers on that, you might think about what if this option were extended to all of those with serious chronic diseases.

But we would, in response to Dr. Konigsberg's comment, like to go through each of these and really get your reaction as we go, and we are fortunate I have Dr. Lee and Dr. Coye and Dr. Makadon and Tim Westmoreland here with us to also talk about these. So we would like to start with the first option that we have got in the paper, recognizing that comments that say hey, there is another option here you haven't thought about, you ought to include that, we are eager to get those comments as well.

So that we will turn to Chart 16 and the first option under Medicaid.

COMMISSIONER KONIGSBERG: Could I just make one little editorial suggestion in the executive summary? It

sounds like a picky point but it really isn't to me. It uses the phrase "current private health insurance plans and public health financing programs provide adequate coverage."

I would suggest that that "public health financing" be changed to "publicly financed programs" or something of that nature. It gets the issue confused with public health, which is, I think, a little bit -- I think it ought to be more precise. Sorry.

MS. HARLOW: Well, starting with Chart 16, I'll talk a little bit about the first option under Medicaid. Under this option, Medicaid would be mandated to provide coverage to all persons with HIV infection or AIDS with incomes below the federal poverty level and meeting the SSI asset test. We estimate under this option that 11,200 individuals with AIDS would receive coverage, and an estimated 255,000 individuals with HIV infection would also be eligible for coverage, although they may not all accept it.

This option would extend coverage to approximately a quarter of the uninsured population with AIDS, and the total number of Medicaid individuals would increase by about 1 percent. However, I think it is important to emphasize

that this option still leaves many poor and near poor individuals without coverage, and specifically this would mean individuals with incomes above the federal poverty level, which is currently, as I have already mentioned, $567 a month, or less than that.

I think it is particularly important to note under this option that a large number of individuals with HIV infection would gain Medicaid coverage. In terms of all benefits provided, it would greatly improve access to ambulatory and inpatient services, and it would also greatly improve access in particular to early intervention treatments for individuals with HIV infection. Coverage of certain services would vary by states, and this might be particularly true of services such as long-term care or the provision of prescription drugs. Low provider reimbursement rates would probably be a problem again, and it might cause difficulties for individuals trying to find a primary care physician. Additionally, hospitals would carry more of a financial burden by serving a larger Medicaid population with AIDS. I think it is important to note again that states might have a problem in terms of financing, particularly in light of the current fiscal pressures.

We estimate that the total cost of implementing this option in fiscal year 1991 would be $611 million, and this would be split between the federal and state governments; 312 million would come from federal funds and 299 million would come from state funds.

If this option were to be applied to all individuals with incomes below the federal poverty level and not just those with AIDS or HIV infection, the estimated cost would be 15.5 billion in 1991 dollars.

I'll now review is second option.

DR. DAVIS: Why don't we stop for just a minute. I think Ms. Ahrens also made a very important point, that when we have estimated the cost to state and local governments we have not offset the savings to them from reduced say bad debts at local hospitals or the state-only or the local-only programs. So while it looks like an incremental cost of 300 million to state governments, there may be some offsets to that in that expansion of Medicaid would then use federal matching dollars to pick up services that they have now been de facto having to pick up out of their own budgets.

Any other comments or reactions specifically to this option and how it would work? I think the main thing is

it is probably one of the cheaper options.

CHAIRMAN OSBORN: Diane, and then Charles.

COMMISSIONER AHRENS: It seems to me that we are going to have to find some way of addressing the disproportionate burden issue. I don't know how we do that, but it just seems to me that the states that -- the populations that need it most are in a very few states who have the least resources to do what we want done, and I don't know how we get at that, but I'm just afraid that anything that we propose in this area may just go down the tubes because of that kind of resistance, which I think will be taken very seriously.

The other -- I am wondering if there is any way that there is anything in this that we can -- that would be covered or any advantages gained by going this route, that if we find there is a impasse here is there anything we can cull out of this that you could do another way, that we could get at another way?

DR. DAVIS: Well, one approach, but it is politically very difficult, is to change the federal/state matching rate, that you could shift more of this burden on the federal government by just changing the matching rate of

services. That tends to get very controversial because then everyone looks at how their state, their district is affected by that. But certainly there have been proposals that as the federal government is expanding Medicaid they need to increase the rate.

The other issue, and I believe the National Governors' Association may be looking at this, is rethinking the sorting out of what the federal government is responsible for versus state government, so you could trade-off benefits. The federal government could pick up hospital and physician services for all Medicaid beneficiaries, the way they now do basically with the elderly, because states can buy the elderly into Medicare. And there have been ideas about letting the states but the nonelderly Medicaid population into Medicare, which shifts most of that cost onto the federal government. And then the states would be picking up supplemental benefits and maybe the long-term care benefits with federal matching funds. So those are some of the options of dealing with that federal fiscal problem.

CHAIRMAN OSBORN: Phil?

DR. LEE: Just I think in terms of the analysis, Karen, it would be helpful in your background document along

the lines of this suggestion that you provide more information on New York, California, Texas, Florida. They have very, very different Medicaid programs. California and New York have some of the broadest eligibility yet some of the lowest levels of provider reimbursement, so they basically deny access, particularly for primary care. And also, even if you provided it and if you covered some of those let's say IV drug users who might be eligible, what impact would this really have on access? In other words, if there is more information? Because those are the big impacted states.

And then there are the sort of second tier states, but I think if you could even look at those in more detail so that as you develop this option, one, you would have a better sort of you might say political fix on it as well as where the impact of the epidemic is strongest.

COMMISSIONER KONIGSBERG: Just to kind of pick up on some of Diane's points a little bit, and again from just practical experience in dealing with Medicaid. While I think we should consider some tinkering with Medicaid as part of a complex of options, I guess I'm pretty skeptical, or maybe cynical. I have never had I guess the misfortune as a state

health official to have Medicaid under my purview and I have always been able to say, well, that belongs to the social service agency, and then I can find advantages and disadvantages with it that way.

However, every time I go out into the hinterlands the first thing people want to talk to me about, especially physicians who may not know how state government is set up, is Medicaid, Medicaid, Medicaid, complaints, complaints, even complaints about things that Medicaid and the state fixed a long time ago. That it is going to be very hard to overcome. There is a stigma attached to Medicaid.

My own personal experience with trying to see how Medicaid is supposed to help with the delivery of perinatal services, prenatal care and delivery, has been very dismal, and I think at least some of our state legislators have realized that they have got to make some systemic changes as well as raise provider reimbursement rates and streamline paperwork, and I just see this as kind of falling into the same pattern.

Now again, politically, to the extent that I know, that sounds like that would be very easy for Congress just to stick this off on Medicaid and get the states to pick up

half, and I can tell you, the governors are mad as hell and they are not going to take much more about increasing the Medicaid mandates. The last resolution that I saw from NGA, 49 out of 50 governors said no more Medicaid mandates, and the only reason there was one missing out of that, he just wasn't at the meeting.

Now, I don't know how we resolve this, but somehow the Medicaid is a pretty dam sick system in a lot of ways and yet we are in it so deep I don't know how we get out of it.

MR. WESTMORELAND: I'm sorry, I'd like to provide a couple of suggestions as to what you have talked about and things that we have considered on our staff as we have worked with Medicaid legislation. One of them, as you can see from the estimates in the first bullet here, the vast majority of the people who are helped by this proposal are HIV positive but not AIDS. One of the proposals we used and considered as we were putting together our Medicaid proposals for AIDS and HIV was deleting the eligibility for acute care hospitalization and long-term care for the HIV positive population. That still leaves those people with a hospital need, but those people are by and large in less need of hospitalization than anybody else in this crowd, and it gives

those people the option of getting prescription, drug and physician and outpatient primary care without having to pay for the expensive hospital care.

I can rationalize that in my own mind because most of the time when people convert to the need of needing acute care of long-term care -- if it ever comes about that anybody gets long-term care -- but acute care, they have crossed the line into the definition of AIDS, and by that point they are already eligible for most Medicaid services. So what you are insuring by paying for hospital and long-term care in this bunch of people of HIV positive, I think it may in many cases be not HIV or AIDS related; you may be paying for their car crashes or their labor and delivery or something like that, but not their AIDS and HIV services. So one of the ways we ratcheted down for the large bulk of patients here was not providing those most expensive services while still getting them the drugs and physician care that they need most.

DR. DAVIS: I think out of that 611 million, 124 million of it is for the HIV positive population. I don't know what proportion of that is hospital care, but I suspect you are right, a good bit of it could be.

MS. CHU: Karen, we didn't include any hospital in

that for the HIV.

DR. DAVIS: Sorry, I guess we have already trimmed that down. We have assumed, like you have assumed, that they would then go into the AIDS group.

DR. LEE: As you know, in Hawaii with this latest increment of state funding, they basically are providing primary care for those who are uninsured, and six days of hospital care. So the principal has been established. One could look at the Hawaii experience -- and I actually know you are on this group that is going to evaluate that -- and that might be worthwhile to use that as an illustration of here is an approach that has been taken in one state and see how that plays out.

MR. WESTMORELAND: The other thing that I was going to mention was this option is laid out as mandating Medicaid coverage, and as Dr. Konigsberg has alluded to, the governors aren't very happy with mandates. But right now in the legislation I have been working on to provide early intervention care for HIV positive people as an option, we have been getting significant support from some of the disproportionate share states that New York and New Jersey and California have all voiced a lot of interest in providing

early intervention care.

Now, that fragments the system so that PWAs and people with HIV in Texas and Florida are still out of luck, because those states are not going to walk up and volunteer for it. But if you are looking at a way of phasing something in and experimenting with something and trying to trim prices, making it an option with federal matching instead of a mandate might do it.

COMMISSIONER AHRENS: I think it is important though that we take a look at the impacted states in some detail. What concerns me is the issue that Phil raised on the access. We may think we are really accomplishing something when we aren't if the rates of reimbursement are so low that physicians aren't going to respond. I just think that we need to take a real look at that to know whether or not we are buying something that is realistic.

MR. WESTMORELAND: But at least in the HIV positive population alone, these quarter million people here, the benefit that I think all of us would agree they most need is prescription drugs and primary care, and Medicaid actually pays prescription drugs pretty well so you can buy access for those, and if you could find a way of fixing the physician

access you would do a long way.

COMMISSIONER AHRENS: But as long as it is set by the states and the reimbursement rates are set by the states --

DR. COYE: Unfortunately it's the primary care piece that's in the worst shape in Hawaii.

CHAIRMAN OSBORN: Let me get people new to the microphone system to know that there is a red light that goes on.

DR. COYE: Unfortunately it is the primary care piece which is in the worst shape, and that speaks I think to the idea of thinking experimentally about some cross-over combination of a Medicare model and a Medicaid model. I don't know what is practical in terms of what is acceptable to Congress, but the attraction of the Medicare model is the idea of reimbursing better for the primary care.

COMMISSIONER OSBORN: Harvey Makadon.

DR. MAKADON: Yes, I agree with Molly's comments about the need to think about how we reimburse for the primary care, and it is not just so much of the per visit amount. But some of the estimates, for example, I think it came from one of Jessie Green's papers, that was four visits

per year for someone who is HIV positive and six visits per year with someone AIDS. If we are going to base our cost estimates on that kind of model, I think that it might be better than what some people are getting but it is hardly adequate to provide adequate care for someone with AIDS or HIV infection.

So a real issue that I think the Commission needs to think about is what really is an appropriate model of primary care, what is realistic in terms of the number of visits we should anticipate, and what is reasonable to reimburse for those visits, and then to go back and think where should that fit into the financing model. Because I think we really need to look at what our goal is in terms of the nature of the primary care system as opposed to looking just at the options and thinking about what's -- I mean, I think we have to do both, but we can't just think about what is the most politically expedient option, we really need to think about how to build this model of care.

And I guess another of my concerns is that we really try and build it in a way where HIV care, early intervention and care for someone who is HIV positive and care for someone with AIDS are part of one system as opposed

to things which are funded differently because we can't make this kind of crazy financing system sort of work in concert.

CHAIRMAN OSBORN: Don Goldman, then Charlie and then Eunice.

COMMISSIONER GOLDMAN: Do all the states provide prescription drug services under Medicaid? What is the number?

MS. HARLOW: I don't know the exact number, but all states don't necessarily provide them.

MR. WESTMORELAND: Forty-eight states provide some form of prescription drug, but it varies wildly what they will cover. I know, for instance, when I went back and found Kentucky will cover any drug on the marketplace but will only pay $25 for it.

DR. LEE: Well also didn't Florida exclude AZT, but now they have included it, right?

MS. HARLOW: All states cover AZT under the categorical program.

DR. MAKADON: I think we should also note that it is not just Medicaid that is sort of spotty in terms of covering prescription medications. Even people with private insurance who might be somewhat marginal in terms of their

income have a very bad time getting drugs because that is now increasingly not covered by a lot of private insurance plans. That's a sort of general issue I think.

COMMISSIONER KONIGSBERG: I want to come back again, it is hard for all of us I think to separate the financing, or one specific aspect, from the whole system of care or non-system of care we have out there. One of the things that really troubles me, and I think Medicaid kind of fits right into this, is that if we are not careful with this early intervention system, which I think we all agree is the right way to go because it's the right kind of care and it has a strong prevention overtone, but one of the dangers we have is that we'll be setting up separate systems of care much like the old TB days. I have a real fear of that.

The reason I have a fear is partly due to categorical financing, but more fundamentally because I'm not sure that the system out there is geared to deliver this kind of care, or to be more blunt about it, that physicians really understand early intervention or want to take care of these patients. I know in some comments I made to second year medical students at the University of Nebraska last week I put up that time line -- not the iceberg slide, I don't use

that anymore, I use the time line -- and tried to get them to see as primary care physicians, which I think many of them in that state will wind up being, how much to the left end of that time line they have got to deal with, including the risk factors before infection. I didn't dwell with the end-stage HIV disease, figuring that they would refer that.

And I just am very skeptical, just based on my own experiences not just in Kansas but elsewhere, that we have got a system out there that is ready for this. And, of course, Medicaid is seen as a poor person's program and that's another type of segmentation. I really don't know what the answer is to it, but somehow when we get down to the point of what goes into this paper we have got to deal with that and then some suggestions on how to get physicians and others ready for what they are going to have to do.

CHAIRMAN OSBORN: Eunice, Molly, Phil. And we do have a bunch of other options so that I think that about at that point we might want to keep on going, and then we can revisit some of the earlier ones as we go.

COMMISSIONER DIAZ: I guess I'm having difficulty looking at the various options and reading through this material when we really have not yet had an opportunity to

build consensus about what kind of care or system of care we are talking about. If we are talking about the provision of HIV care within an already established primary care system or hospital-based system or a defined case management system, it would be much easier to consider how that type of care ought to be financed. But without very explicitly saying this is a portion of that extensive amount of care, I guess what prompted my question was Tim talking about really segmenting the kinds of medical care or health care needs that a person who is HIV positive might have throughout the entire spectrum of their life.

I think if we are talking about comprehensive care for all people that become positive or at risk for HIV and eventually later my develop HIV disease and have terminal manifestations of disease, that's something totally different than looking at what we could provide with a system that was primarily looking at an early intervention package and then an ambulatory package and a hospital package and maybe after-care or home care.

So I'm having difficulty looking at financing options when we really have not defined a system that we think would be necessary or adequate to meet the needs of

these populations.

Are we basically looking at these options today at the provision of comprehensive medical care, looking at what that implies, the total scope of physical, mental, social, psychological, emotional support throughout the entire spectrum of HIV positiveness until death? Is that basically what we are talking about?

CHAIRMAN OSBORN: David, why don't you take that?

COMMISSIONER ROGERS: Let me just build on that, because I have the uneasy feeling we are going to get down to trying to micro manage the financial system and I wanted to just build on what Eunice has said. It seems to me, if I heard Harlon and others earlier, we have said what we -- and I think we should continue to paint with that broad brush. We have got people who have spent 20 years of their life defining the specifics of it, we want to sort of set the agenda. And I heard earlier we are generally agreed that we want some kind of universal coverage, or specifically, without a primary care system in place, all of our recommendations regarding those who are HIV infected will fall short. That is sort of a big general thing which this Commission could say without having to micro manage the

system.

Number two, that we then must offer some incremental steps, which I don't think we need to do in great detail, but to relieve the immediate suffering we have got to have some things out there that say we have got to move head with these right now and we are going to try and design those so that they don't interfere with that objective of getting that universal coverage. And then I think I have heard pragmatically and practically it shouldn't be just HIV targeted, perhaps we should broaden it to those with chronic relapsing illness to buy on more into what we do.

Now, I hope we move on. I found this helpful as we defined each of these options, but I don't think we should carry it down to the very refined specifics because, one, we are going to miss on them, and it seems to me this Commission's role is to say here is what we must have, these are the big broad things we must have in this nation if we are going to do what we say we are going to do as a people.

And then it is for the Karen Davises and the Tims and others to work out precisely how we get there. I don't think we should worry to much about the micro steps in this, what will satisfy Charley or what will satisfy me or what

will satisfy Diane or whatever. We will never get there if we try to do too much of that specific stuff.

CHAIRMAN OSBORN: Molly and Phil, and then let's proceed.

DR. COYE: This sort of follows on what Charles and Eunice were talking about, but I think it is fairly complementary to what David was saying. Two points. First of all, from reading the transcripts of the Commission in the past there has obviously been a lot of discussion about the need for a continuum of services and of the nature of the kind of care that you would like to see made available for people who were HIV infected, and need for regional networks and the aspects of the Ryan White bill that really promote that or attempt to try and foster that kind of program. And it might be very helpful and interesting to get comments, either now or in the written report, about the incentives and disincentives in the reimbursement streams being considered towards the development of those regional networks of cooperation across different types of providers, because most of these reimbursement streams are very specific to particular provider types and settings. And one of the persistent problems has been to build systems that make

sense, not just for HIV but for all kinds of provision of care.

And if there are ways that the Commission could recommend through expert consultation to amend the nature of these programs to promote primary care and integrated networks, that that could be a very specific way of calling attention to how the system as a whole can learn from HIV in a way that I think could be very exciting.

A second example of that is a lot of the work that has been going on in the last year or so looking at the integration of primary care and substance abuse, much of it stimulated by the provision of care for HIV infected people. And I think that drawing on those examples, those demonstration projects, we should also be looking at from the reimbursement point of view how that reimbursement stream and that program system, that set of functions, is going to be integrated into this continuum of services. Because a growing proportion of the HIV infected are also receiving services and will need to receive services for substance abuse. And is the whole issue of how that takes place with primary care and what can be learned from the early demonstrations about the financial aspects of that, you know,

I hesitate to say combining them because there are all kinds of different models and that means different things to different people.

But I think that's the biggest question financially to me. If I were a state official looking at this document I would say, well, most of these people -- you know, a third of these people, a fourth of these people -- are also in a substance abuse treatment program or should be or will be as soon as they get into early intervention treatment. How do those reimbursement and treatment systems interact and how should I be dressing that.

The Commission may not feel ready to answer that, but if there are any early answers it would be of great interest I think to hear of that.

DR. LEE: As the Commission looks at the question, there are I think a couple of facts that are very important. One is that the epidemic isn't a single epidemic. There are marked differences geographically. We have been looking at the 16 communities with the largest number of AIDS cases, and clearly there are certain characteristics in New York and New Jersey that make the epidemic totally different than in San Francisco, Seattle, Los Angeles, Houston, Dallas, Fort

Lauderdale. Miami is a different epidemic also. And it seems to me then you have that variable. The second is the state policy variable. And the third is the local government. New York is unique in the Health and Hospitals Corporation, the percentage of people in New York that are cared for in that system.

Texas and California, very different in terms of the role of local government and state government. Texas delegates very significantly to the counties. California has a much larger role for the state and a much larger Medicaid program.

So I think in the major states you need to look at each of those variables as we analyze whether the Medicaid option is a good option or not a good option. So it makes the problem more complicated, but at least as you advise Congress or the state governments, and indeed the private sector -- but I see your audience as principally Congress -- you can then say these are the things you have to consider. You may not have time and there may not be time in this analysis to do that, but I think those are the kinds of variables in terms of ultimate policy decisions that have to be kept in mind.

CHAIRMAN OSBORN: Perhaps now is a good time to proceed, Karen, and then these issues will keep on surfacing and as we work our way through the day I have a feeling that some of this can jell.

MS. HARLOW: Okay. You will find Option 2 on Chart 17. Under this option, Medicaid would be mandated to pay the health insurance premiums and maintain or restore insurance through the workplace for a minimum of 29 months for persons with HIV infection or AIDS who have left employment with incomes below the federal poverty level.

We estimate that Medicaid coverage would be extended to 4,100 individuals with AIDS under this option and 8,000 individuals with HIV infection. This option, however, does not extend Medicaid coverage to many individuals who were previously uninsured. We estimate this to be 2,400 individuals.

Additionally, this option extends coverage to a very specific population who had employment and also who had health insurance coverage through their workplace. Employers would field the cost of this option and premiums would be increased to finance the cost of AIDS and HIV related health care benefits through the workplace.

A benefit to this option is that it would extend private insurance, which is generally more attractive than Medicare or Medicaid, particularly in terms of the reimbursement rates to providers and the benefits which are provided. And also, because individuals would be maintaining their original insurance policy, they would probably be able to maintain their current primary care physician and not have to change. And additionally, financial burdens on hospitals would not be increased because reimbursement rates would be more generous.

I think something to keep in mind for this option is that it is currently being implemented in a number of different states. In some states it is being done as demonstration projects, but in Texas there is currently a similar premium paying policy for all individuals with a chronic or terminal illness.

Under this option we estimate that there would be a net savings to the Medicaid program of $123 million, and essentially this savings would occur because Medicaid would now only be paying the cost of the premium rather than the cost of all the services used.

CHAIRMAN OSBORN: Don.

COMMISSIONER GOLDMAN: One of the problems with this program, as you pointed out in your paper, is that I guess it only applies to those large employers covered by COBRA, and that with respect to smaller firms even if they were included in some way they would be terribly hard hit to the extent that their premiums were experience rated in some way.

And you didn't mention it as an option, but one of the thoughts that I had in reviewing the paper to deal with some of those problems might be to provide, for example, an option on the part of small employers across the country to buy into the Federal Employees Health Benefits Plan, which would then enable them to spread their costs over a large group of people and then for that bought into that, then COBRA would be deemed to cover them and some of the administrative problems in terms of saying, well, it is not fair to small employees to have COBRA wouldn't apply, and you could expand the COBRA kind of provisions. You could probably appease the private sector as well by saying that if they wanted to set up a similar competing plan similar to the FEHB that people could buy into as a national plan with equally broad based coverage, I suppose something like that

could be worked out, but some plan on a national basis. Again, my idea being to try to broaden the base as much as possible for as many people as possible.

And I think the reality is that none of these systems that we are going to do deal with on a piecemeal approach basis is likely to be a very viable solution on a stand-alone basis. It is only when you are dealing with different pieces of pie which are going to cover different people for different services. I mean clearly, for example, Medicaid alone has its problems and Medicare alone has its problems, but if you can get somebody covered by both Medicare and Medicaid, it is a pretty neat fit in terms of some of the things that are covered back and forth. And likewise with respect to some of the insurance proposals, and we ought to look at putting these things as different pieces of a whole puzzle to provide services rather than trying to do the whole thing. Because when you start doing the whole thing you end up really dealing with universal health insurance and you end up back at that 10 year future projection.

CHAIRMAN OSBORN: Phil.

DR. LEE: Just in the analysis, Karen, it seems to

me -- and this was discussed, as you know, at this Ways and Means retreat -- one of the down sides of this opposition is the opposition of the insurance industry, which you don't mention. Now, one would say how can they, this is really -- they should continue to cover people who are sick. The fact is we have to provide coverage. The insurance industry will oppose it. They do oppose it. And also, employers can simply self-insure with ERISA and avoid this if they are hooked with it.

The third thing that we have seen in California is even those with private insurance shift to Medicaid because Medicaid has a much better benefit package when you are chronically ill, when you have AIDS and you need long-term care services, which are not included even in the better private packages. So that this I think is a limited option. It seems attractive because it does save some Medicaid money, but I think there are some down sides to it.

DR. DAVIS: Well I think that's good. I think you have highlighted some of the drawbacks to this option. I that Mr. Goldman's comments particularly about how this is really not getting at the bulk of the people who are working. The COBRA provisions do just mandate for employers with more

than 20 employees they would provide the option of continuing your coverage in force, if you pay the premium, for 18 months, and then the changes in '90 that extended that to 29 months, but only if you leave the job because you are disabled and then only if you have 70 or more employees. So then that narrows it further.

The idea you have of letting small business buy federal employees is one I haven't heard before that I would like to think about. Some other ideas that are out there are setting up state risk pools for small business and the idea of letting small business buy Medicare coverage. So I think that's also one that we would like to think about.

I would like to turn then to the next two options with regard to Medicare. Chart 18 talks about the option, which is voluntary, of letting SSDI beneficiaries buy Medicare coverage. They would buy it by paying, taking advantage of a provision now that let's elderly people who for some reason aren't on Medicare buy hospital and physician coverage. They have to pay the full actuarial cost of what is called Part A, or the hospital part of Medicare. So if you are an immigrant who didn't have work history, didn't get qualified for Social Security, you can buy Medicare hospital

benefits but you have to pay the full cost.

What we are assuming in this option is that SSDI beneficiaries would buy Part A by paying that average premium, not a premium that is specific to the SSDI/AIDS/HIV population, but what these elderly, say an immigrant person, would be paying now to buy Part A. So when you first think about it it seems like it would be a free option because the SSDI beneficiaries would be paying a premium to cover their costs, but it is the average cost of elderly and disabled people. So since this is a very sick group there is a net cost to the government.

The other part of this option is that if you are poor and on SSDI then Medicaid would be supplemental to Medicare. They would be paying this large Part A premium, they would be paying your Part B premium, they would be paying your deductibles and coinsurance.

We estimate there are about 38,000 people on SSDI in that two-year waiting period, and so any of those people would if they wanted to under this option buy the Medicare coverage. Of them, about 7,000 have incomes below the poverty level, so for them Medicaid would then be supplementing Medicare. So since many of those are eligible

for Medicaid as disabled, we can be sure that the Medicaid programs would take advantage of that and pick up their premiums to buy them into Medicare.

In addition, there are another almost 5,000 out of that group who we would expect to buy Medicare. Well, why wouldn't all of them buy Medicare? The problem is that this premium is just prohibitively expensive. If you take what is now charged for the Part A cost of buying hospital benefits under Part A, and the B, you are talking about $3,500 for that premium. So you are talking about $300 a month roughly. So if you are getting SSDI cash at five or six hundred dollars, to have to devote $300 of it just to buying your Medicare coverage when you may need that money just to live on, eat, pay rent, mortgage, et cetera, it could be prohibitive.

As much as that is, you should also be aware that even when you pay the three hundred a month to get Medicare, Medicare doesn't cover prescription drugs, some other types of services, so that's not the extent of what you are going to be paying. Altogether, you know, you could be paying $12,000 easily under this option by the time you pay your Medicare premium, you pay for your drugs, other kinds of

services.

On the other hand, it does get you into a good program in terms of coverage of physician services, hospital services. Provider payment rates, while they aren't as high as private insurance, are reasonable. Most physicians and hospitals participate in Medicare and those services would be available to you.

The cost to Medicare of this option is $715 million to let those who want to buy this Medicare coverage, and this is the cost -- over the $300 a month that they pay -- the actual cost to the Medicare program of providing their hospital and physician services. On the other hand, there is a net savings to the Medicaid program of 239 million, because many of these individuals in that two-year holding pattern are getting Medicaid coverage to pick up their hospital and physicians bills, and that would then be shifted primarily on to the Medicare program. So that's how that option would work.

I owe some credit to Mr. Goldman for actually having suggested this for our consideration.

COMMISSIONER GOLDMAN: In the cost end of the data, you used the $60,000 a year number that has been developed

and jacked it up to 75 and then subtracted out some stuff.

Is that number based upon the cost of providing care or is that number based upon the Medicare rates of reimbursement for that care? And is there a difference between the two?

MS. CHU: Actually it is the cost of care. I assumed that Medicare pays hospital costs, and that's pretty close to the truth. Most hospitals don't make money on or gain much money on Medicare. I didn't take into account the slightly lower reimbursement rates for the physician services, but it would be about the same ball park.

COMMISSIONER GOLDMAN: Okay. The other point that I would make is that the numbers that you use here, you know, obviously demonstrate, with respect to an AIDS population, given its high cost, the kind of cost numbers that you have. My understanding is, and at least on the data that I have seen -- and I guess I'm mostly relying on the work done by Barry Bayh and Jerry Riley -- that on the average for the two-year period that it looks to me as if the average cost of care is about at the most 150 percent of what the premium is. It looks to me as if the average cost of care during that two-year period is about one and a half times the average

cost over the lifetime of the period, and that therefore the number that -- you know, you are using numbers in terms of, you know, the 60,000 versus the 3,500, when if you expanded it to a much larger population you would be talking about a difference perhaps of maybe $1,500 hundred or $1,000 per person in terms of the differential between what the actual actuarial cost is and what the cost of providing services might be.

MS. CHU: I have looked at some Medicare actuary data on extending this program to get rid of the two-year waiting period to all disabled SSDI persons, and I think it would be about 50 percent more expensive than the average disabled person now, but, of course, we are talking about the AIDS population, which is even more expensive than that.

COMMISSIONER GOLDMAN: The other question is, and maybe somebody else can answer it, the papers that I have seen have assumed for this purpose that most of the savings and the basic rationales for why Medicare doesn't cover the first two years is that a large number of the people die during that two-year period and therefore never require services. And one of the estimates that I have seen is that approximately 80 percent of those who have AIDS who qualify

for Social Security die prior to the two-year period in which they would get eligibility, or at least that's in a footnote in the Bayh and Riley paper.

And I'm wondering whether or not anybody thinks that still would be true today, and whether or not we are talking about a population that is likely, given some of the newer modalities of treatment even, and particularly for opportunistic infections and others, that probably are likely to end up being on Medicare anyway and that the actual cost of providing care, which is heaviest in the last year or two of life when the hospital costs are high, are likely to be extended, and we are talking about perhaps not $60,000 a year for perhaps a two-year period or an 18-month period, that we are talking about perhaps a lesser sum over a longer period of time, and whether or not the assumptions even that you are making in fact look like what AIDS costs are likely to be in two or three years when any such program like this might be implemented?

MR. BIALEK: I think I can address that to a small extent. There have been some recent studies, including Ann Sitovsky, which showed that AZT might prolong life somewhat. There have been some indications in some other studies.

Other studies have not shown the same. The problem that exists is that if AZT and/or pentamidine increases life, it is not known whether the cost of hospitalization during the early part of that treatment, the reduced cost, is offset by the increased survivability. That's unknown at present. The studies show that there may be a trade-off right now. No one has gone any further into that.

DR. DAVIS: We had hoped to do, and still hope to do, three-year cost estimates once we kind of narrowed these options down to those that you are particularly interested in so we would look at '91 through '93. Obviously, our confidence in these cost estimates is also going to diminish as we try to do that, both because of the uncertainty about the number of people, but also the very important point you are making about potentially varying care patterns and needs for care of this population over time.

MS. BYRNES: Plus if you are relying on Medicaid to pay for your AZT, you have already got full blown AIDS, so it is not going to take into account anybody with HIV infection on Medicaid because you can't get Medicaid to pay for your drugs, so those numbers are going to vary widely dependent on when you decide to count.

MR. WESTMORELAND: I think this is as good a place as any to sort of inject into this discussion the very difficult cost accounting problem that I run into all the time in dealing with this area, which is as the advent of drugs continues and as we can prophylax against more and more conditions and prolong life, the Congressional Budget Office and the Office of Management and Budget continue to keep giving me estimates back which charge us both for the cost of the prophylaxis and for the hospitalization, because there is no good data showing the days of hospitalization are actually averted even if you prophylax.

The disease and the treatments are so new that you cannot demonstrate to the satisfaction of any actuary that by giving aerosol pentamidine or bactrim or Septra or whatever that you are actually keeping people out of the hospital in the long run. Because even if you assume that it is a hundred percent effective, they may end up in the hospital three years out with toxoplasmosis instead, and we just don't have the data to deal with.

But the other thing, and I think an important thing for this to Commission to understand when you are dealing with cost data like this in the agencies that I work with, is

that there is a basic assumption that it is cheaper for people to die sooner. And you have got to understand that those systems are costed out that way and make a moral stance of whether that's appropriate or not as you design a financing system. Because years ago -- and Karen will remember this even better than I will -- in like 1981 where we were trying to put the pneumonia vaccine into the Medicare program, HCFA estimated that the cost of doing so would be wildly expensive, and while it is an expensive vaccine it is not that expensive. But if you went back into the estimates of why HCFA thought it was so expensive, it was because the elderly people who weren't going to die of pneumonia were going to collect on hip replacements and heart transplants and other kinds of surgery. And the underlying premise is essentially if the elderly will die on time the Medicare program is better off.

As you do all these kinds of estimates of the changing modalities of treatment and how we provide for early intervention care versus acute care, you got to recognize that most of the systems we are working within and most of the ground rules for the budget assume it is cheaper for people to die soon.

CHAIRMAN OSBORN: As a matter of fact, I'll take a second to interject a story that Tom Brandt will remember with a shudder. I was giving an interview on CBS national radio to an interviewer who does that sort of thing all the time right after the prison report came out. And he asked part way through the interview with a perfectly straight face, you know, you say here that prisoners live only 180 days and other people live 312 days, but they have got to die anyway, what's wrong with that?

It stopped me absolutely cold for a couple of seconds because this was supposed to be on national radio. So when Tim says that, if he sounds like he has had one too many years on the Congressional staff, I support him. There are an awful lot of people out there, and somebody will even say it out loud.

COMMISSIONER GOLDMAN: I just want to add, there was one other component to the proposal that I suggested to Dr. Davis that is not reflected in here, and that is that perhaps the idea that -- one of the things we observed, and particularly at some of our visits across the country, is the fact that in many jurisdictions qualification for Social Security disability rises one to an income level that makes

one ineligible for Medicaid.

And while the comment is made that it is a terrible burden on people getting only $500 or $600 a month on Social Security to have to pay $300 a month towards their own Medicare premium, part of the concept that I put together suggested that part of the system would also be that that money would be deducted from their monthly payments before they ever got it so that therefore their monthly payment would be reduced to $200 or $300 month, which would then provide them with a low enough income that since they are already disabled they would qualify for SSI and then have Medicaid on top of it, which would also solve some of the problems of the inadequacies of care and coverage that presently exist in the Medicare program.

And from the states' perspective, while they might be getting more people onto a Medicaid program and onto a public assistance program on one hand, on the other hand, they would be taking a bunch of disabled people who would otherwise be qualified and replacing federal Medicare dollars with state matching dollars on the other hand and it might be attractive to them and it might be a package that could be put together.

I don't know whether it can or not, but that was part of the concept of what I was looking at, not merely the Medicare coverage piece alone.

DR. DAVIS: Maybe we should move on then to the next option, and this one goes further than Option 3. Option 4 would actually eliminate the two-year waiting period. And why that's different is that instead of having to pay this $3,500 a year premium to really pay the actuarial cost of the hospital part of Medicare and your Part B cost, for a typical Medicare beneficiary you would only have to then pay the Part B premium that Medicare beneficiaries currently pay, which just covers physician services, and actually only the 25 percent of that cost of Medicare.

So instead of talking about a $3,500 a year premium we are talking about a $350 or $360 a year premium. In other words, we are talking about $30 a month, not $300 a month, to be covered. So eliminating the waiting period means you are treated like any other Medicare beneficiary, you only pay a much more modest Part B premium.

This option, like Option 3, would also keep Medicaid supplementing Medicare coverage for poor SSDI beneficiaries. So now the Medicaid program would be paying

that $30 a month Part B premium, would be paying the deductibles, the coinsurance for the poor beneficiaries who are covered under Medicare as well as Medicaid.

So this option would reach all of that 38,600 SSDI beneficiaries in that two-year waiting period. It is automatic, it's not voluntary. Well, to some extent it is voluntary since Part B coverage is voluntary, but we can assume that everyone would take advantage of this.

And so the 7,000 out of that group would also be dually eligible for Medicaid. Medicare coverage would provide really fairly comprehensive coverage for ambulatory care and inpatient care, but again remind ourselves they are not as good on prescription drugs and long-term care services.

Now since Medicare would be the primary coverage for these individuals, some of them will have supplementation from Medicaid, but there may also be people who would have supplemental benefits from an employer plan that would be picking up these deductibles, or may purchase what are called medigap policies individually to go with Medicare. So again, some people might be filling in some of these deductibles with some other kinds of coverage.

Again though, to the extent that they don't have supplemental coverage for things like prescription drugs certainly they are going to be paying far more than $30 a month if they have got to pay their drug bills out-of-pocket.

We estimate that the total cost to Medicare of this option is $2.5 billion in fiscal 1991, so it is one of the more expensive of the options. There are savings to the Medicaid program of almost 200 million because some of these SSDI beneficiaries are covered currently by Medicaid.

We do have an estimated I believe from HCFA actuaries of what it would take to eliminate the two-year waiting period for all SSDI beneficiaries, and they put a price tag at something like $6.1 billion in calendar year 1991.

COMMISSIONER DALTON: A quick question. As I understand from your paper, the purpose of this two-year waiting period is to try to help distinguish between chronic illnesses and those that aren't. I wonder if HCFA or anyone else has an estimate for the cost of putting this program into place not for all SSDI recipients and not for those who have an AIDS diagnosis, but for people with chronic illness?

DR. DAVIS: I suspect most of it is chronic in that

to qualify for SSDI the phrase is you must be permanently and totally disabled. So it is not temporary, it is not something you will be able to recover and get back to work. Permanent total disability.

In terms of the rationale for this two-year waiting period, truthfully, I don't know. It came in in 1972. One always suspects it is more a budgetary reason than any sense of we will wait until there is a real chronic need for health care services. I doubt that it was the care pattern, but I don't really know the history of that legislation in terms of why it started with the two-year waiting period.

CHAIRMAN OSBORN: Phil, do you know, by any chance?

DR. LEE: I don't know why that was restricted in the way it was, but I think it is clear that the costs are a big barrier to extending the benefit to at least all of the disabled who are covered.

MR. WESTMORELAND: I too don't know where it came from, but I think you can interpolate backwards by seeing that there is already a five-month waiting period before you can get SSDI. I mean, "permanently and totally" could be dealt with presumably by the five month, so I think the 24 month additional is a simple rationing device.

COMMISSIONER GOLDMAN: You indicated, I thought, if I'm not correct, that expanding all the Option 4 to all the disabled would be $6. 1 billion in 1991 dollars; is that correct?

MS. CHU: That's what the Medicare actuaries project.

COMMISSIONER GOLDMAN: And you suggest that doing it just for patients with AIDS cost $2.5 billion, which represents -- I'm trying to do the numbers -- it is like 40 percent of the -- 40 percent of the total cost of expanding disability is persons with AIDS? I mean, I hate to get that out because then you get an expansion of Social Security with excluding everybody but AIDS would be a more likely result if those numbers -- those numbers don't make any sense to me. Either your number of 2.5 billion is wrong or Social Security's 6.1 billion is wrong, because those numbers just don't make any sense to me. Or maybe I'm wrong.

MS. CHU: I asked the Medicare actuary who did these projections and she said that they took into account AIDS, so it may be the other people aren't that expensive. That's the only explanation I can come up with.

DR. DAVIS: I asked the very same question because

we both have those same numbers leaping out at us. And we did cross check with HCFA and they think they are consistent.

COMMISSIONER GOLDMAN: HCFA thinks the numbers are -- your number of 2.5 billion is --

MS. CHU: I gave her our number and she didn't laugh or anything, so I don't know what that means. She did ask me what our estimate was.

COMMISSIONER GOLDMAN: Well, okay.

DR. LEE: What I think we need to ask them is really to come back again, because of the question about the estimates, and to see if those really are accurate estimates, I mean, on the face of it it doesn't seem to be correct, and I don't think you want the Commission to base some recommendations on estimates where there is some question. And it seems to me they need to be pressed on that as to why they came up with that estimate, when clearly if you estimate the AIDS cost at the 60,000 level, it seems unlikely that those persons would represent 40 percent of the total cost for all the disabled.

COMMISSIONER GOLDMAN: Does HCFA have any data -- I mean, they do cover 2 percent of the people with AIDS, or at least on the chart in terms of that. Do they have data on

what their annual average per cost expenditure per person of those numbers that they in fact do cover?

MS. CHU: I have the numbers back at my table and I will look them up.

COMMISSIONER GOLDMAN: Are they like as much as --

MS. CHU: Let met get back to you the whole two-year waiting period. The 6.1 billion, that's an estimate using about 800,000 people at $7,000 a person. So that's how those numbers --

CHAIRMAN OSBORN: We are coming up to a point where we are going to be breaking for lunch anyway, and so some of these kinds of issues perhaps we could work through during the lunch hour and come back so that we don't lose the main thread of our thinking.

Maybe we should take about 10 more minutes. This discussion continues after lunch, and that will give you a chance as well to check out any numbers that are necessary.

DR. DAVIS: And maybe if we have 10 minutes before lunch, we could just briefly touch on the final major insurance incremental option, which is on Chart 20, and that is Option 5 of reforming private health insurance, and I have asked Ms. Chu to present that.

MS. CHU: On Chart 20 you can see the different kinds of insurance practices that make it difficult for AIDS and HIV patients to get insurance. Health plans for employers with more than about 25 employees generally don't have such restrictions because they have more employees to spread the risks and the costs over. Option 5 would prohibit these restrictive insurance practices. So what would happen is that the cost of AIDS and HIV claims would have to be spread over all small groups or subsidized by other lines of insurance of the insurance companies.

The premiums for small groups could increase, and especially if the cost of AIDS is spread only over certain areas, such as certain cities, then the premiums for all small groups in that area would increase substantially.

Option 5 would also give incentives for some insurance companies to try other ways to exclude small groups with employees with AIDS, or they might even avoid areas with large numbers of AIDS patients.

I will mention a couple of state initiatives in this particular area. In Georgia, a small group insurer with fewer than 50 employee has to pool all of its small group claims together to determine the rate increases, but the

initial rates can include higher rates or waivers for certain medical conditions. And with this program at least two insurers have stopped writing insurance in Georgia for small groups.

Right now in the State of New York there is a community rating bill for small employers with fewer than 50 employees, and that's currently under discussion now. It would have community rating but it would allow pre-exclusion clauses for waiting periods on certain medical conditions. So it is being discussed in the state legislatures right now.

I guess the basic problem with this option is that you can't force employers to keep buying insurance, and it is a little harder to force the insurers to keep selling it.

CHAIRMAN OSBORN: Harlon.

COMMISSIONER DALTON: Was your assumption that this would be federal legislation that would achieve this end? You mention, for example, state initiatives, and obviously insurance is by and large regulated at the state level. But you are assuming federal legislation?

MS. CHU: It would have to be to avoid ERISA type of problems.

MR. WESTMORELAND: The one other thing I would like

to point out in here is that this doesn't do very much in getting either more adequate coverage for the poor under Medicaid or for those people who are uninsured. This is basically a way of getting health insurance for people who are already employed.

DR. LEE: I think it would important also in this background to say what the insurance industry currently is trying to do at the state level in terms of reforms, and I think Carl Schram could provide background information on that. They do have some initiatives that are designed to protect employed workers and prevent these kind of exclusionary practices, but they usually don't apply for employers with less than 25 workers. But I think it would be important just in the background to provide information about what their initiatives are. And I think it would be also important to note the ERISA role, and if you are proposing federal regulation of the insurance industry, that is a very major policy change.

DR. DAVIS: I think those are good points. There is one bill in Congress introduced by Ms. Nancy Johnson and Rod Chandler on the House Ways and Means Committee that would have federal legislation authorize state action in this area.

It is not specific to HIV/AIDS, but it does deal with some of these issues, like you could only have to meet a pre-existing condition one time, you couldn't refuse to write individuals in a group, you couldn't refuse to write a particular group, premiums could only vary within certain bounds, you couldn't charge 50 times as much for a group that had someone who was HIV positive as another. So there are what I would consider serious legislative proposals in the Congress, but it would really be enabling legislation at the federal level to enable states to move forward in this area.

CHAIRMAN OSBORN: Harlon.

COMMISSIONER DALTON: I was just struck, you said Nancy Johnson from Connecticut? May I infer from that that those of her constituents that are insurance companies somehow find this a palatable approach?

DR. DAVIS: Yes, as Dr. Lee mentioned, actually, the Health Insurance Association of America has endorsed some reforms of the small group market. The Blue Cross Blue Shield Association also has a report out on this. So the insurance industry has stepped forward and said that they would support state level regulation, basically, of this market as it affects small employers.

You know, it wouldn't go as far perhaps as some of the things that we are suggesting here. They are also interested in waiving -- having federal law override state mandated benefits so that insurers could offer stripped down policies that maybe wouldn't cover mental health, substance abuse treatment, that might set limits even own hospital or physician services. So there are some other elements of that, and the set that we have put forward, how acceptable that set would be standing alone to the insurance industry again is not as clear.

So I think, as Dr. Lee suggests, we really need to make clear what the HIAA position is if we are going to take this seriously.

MS. CHU: I would also like to point out that the HAY, they endorse a risk pool for high risk individuals. That would maybe spread the risk a lot more fairly, and it could be as a percentage of total business in that state or something.

MR. WESTMORELAND: Very briefly, Harlon, as counter-intuitive as it sounds for some of the insurance industry to support some of this, for a long time the argument has been that they would support some of these

reforms as long as everybody in the industry had to do it, but they have always argued they can't do it voluntarily because somebody will price under them and not abide by the rules.

DR. LEE: The other thing, I just think in the background, Karen, just what you have said about the Nancy Johnson proposal, that information in the background would be quite useful, because it is a set of principles that I think are useful to the Commission to think about in considering this option. And also, with the HIAA, it is my understanding that their basic market is employers with more than a hundred workers, so that it is great to regulate all these fewer than 25 when it really isn't the market for them.

And it might be helpful again to say, if the information is available, sort of where is the market for private health insurance. I mean, we know that most of the uninsured who are working are working for firms of fewer than 100, and many of them for fewer than 25, and how that plays out with respect to this particular option, it would be helpful to have a little more of that information.

DR. COYE: I just wanted to ask a question. Have there been any estimates of what the impact on premiums would

be if these practices were prohibited for HIV? Are there any attempts? Because, again, it would be concentrated in particular states, and my suspicion has always been that it is really a negligible increase in premiums in the face of the 20 percent hikes that we have been seeing in the last couple of years. So I think that in a sense the economics of the increase in premiums could be dispensed with, and that might be interesting and helpful if there were some attempts that could be made to estimate that.

And then we could go on to point out that it is much more the risk of employers dropping insurance or being forced out of the market because of pricing policies that take advantage of this on the part of the insurers but don't really reflect the real costs.

MS. CHU: I made a rough estimate, and if the costs were spread out over the entire country over all small employers, it would only be about a 10 percent increase.

DR. COYE: A 10 percent increase in premiums?

MS. CHU: For small groups, yes.

DR. COYE: Well that's actually pretty big. That's a lot bigger than I would have expected.

MS. CHU: So then if you are talking about some

cities like San Francisco it is going to be a lot more than that.

COMMISSIONER GOLDMAN: That assumes they are all excluding them.

MS. CHU: Well no, I just took the uninsured population and spread them over small employers.

COMMISSIONER: Okay.

DR. DAVIS: But obviously, in terms of a premium, if you didn't have a pooling mechanism, very small firms who had someone in their group would go up a lot. But I think the point that Ms. Chu is really pointing to is that a lot of the advocates of small group market reform haven't stressed is that what you would expect is for the premium to go up, and many of the people who put forward these legislative proposals have suggested that the premium would go down, that somehow these reforms would make coverage more available.

And the only way it would go down is if you had stripped down benefits because you are overrunning state mandated benefits. Or if you are currently a very high risk group, than your premium might go down, but the average premium of the healthier group is going up, and her point is that the average level of this premium, to the extent that

insurance companies know what they have been doing with these underwriting practices and have been excluding people with very high bills, is to raise that average premium.

DR. COYE: I just wondered if there had been any consideration of reinsurance and what that would cost as an approach and how that might actually effectively bring down the premiums? I would suggest that if that is looked at that it be brought to the Commission's attention that probably only 25, 30, 40 percent of employers are going to voluntarily purchase under any of these approaches, but certainly reinsurance would be another way to talk about bringing down the premium costs.

MS. CHU: State pools for reinsurance, it generally only works if the state subsidizes it.

DR. COYE: I'm talking about an estimate of what the cost would be to the states of subsidizing it for how much of a reduction in premium and how that might, given the experience so far with these kind of pools, how much coverage that might lead to as an increase.

DR. DAVIS: I think we made a lot of headway. I think we had kind of wanted to get through all of them, but I think that is a big chunk of the work. It certainly covers

the major five more health insurance based financing options, and maybe we can discuss it more later.

CHAIRMAN OSBORN: Thanks so much. That really is a great deal of progress and a morning's work, and I think we should break now and come back at 2:00 as scheduled. Everybody is on their own I guess as to where to go find a place to eat, and we'll reconvene at two o'clock to continue discussion.

Thank you.

[Whereupon, at 12:30 p.m., a luncheon recess was taken to reconvene at 2:00 p.m.]

AFTERNOON SESSION

2:10 p.m.

CHAIRMAN OSBORN: I think we should probably get started.

For those of you who didn't get caught in the luncheon slowdown, I think most of us did and I apologize for being back a little bit late. Some people are still coming back, but I think we simply overwhelmed the restaurant we all chose to show up at, so their system didn't work very quickly. So apologies to those who weren't involved, but let's get back to work now and resume our discussion of options.

DR. DAVIS: We are going to skip for the time being Option 6 and move ahead to Chart 22 and look at Options 7 and 8 with regard to drugs, since Dr. Beyrer needs to go see patients later this afternoon. So we will start with that and then come back to the provider issue.

DR. BEYRER: Option 7, which is on your Chart 22, is the first option. Basically it refers to the orphan drug law, and Option 8, the second, does not. So I would just preface by saying that these are two ways that we have looked at, and we are going to slip in a third which we have been

discussing over just the last few days. So I'll start with Option 7.

Option 7 would disallow the application of orphan drug law protection to drugs used in the treatment of HIV infection on grounds that AIDS is no longer a rare disease. This would probably impact most strongly pentamidine, which was previously licensed. AZT, of course, was approved as an orphan drug from the beginning, and as Tim Westmoreland pointed out, has patent protection that would carry it beyond the statute of this seven-year exclusivity on marketing, but that would not be the case with pentamidine.

Basically what this would do for the drugs that are approved for the use of AIDS that would be protected by orphan drugs but had previously been used for other indications would mean that they would remain on the competitive market. So you basically would be leaving for competitive market forces to determine prices on those drugs.

This would benefit probably most of the patients with full blown AIDS who are on pentamidine PCP prophylaxis, and the figure that we are using is about 50 to 60 percent of the estimated million people with HIV infection.

The cost to all payers of early intervention and

treatment could be reduced. This would probably not directly reduce the cost for AZT, and as far as implications for other populations with rare diseases that are protected by orphan drugs, it would not have any effect. Equitable treatment for other populations is really not an issue.

Now, as far as the newer anti-retroviral agents, DDI and DDC would probably -- I mean, it depends on how the option, how the committee would be interested in putting forward the option -- but we wouldn't be able to change the patent law as far as their new applications. But the orphan drug protections and research costs, which are saved, could be obviated for those drugs.

Option 8 is to place a price ceiling on drugs used for AIDS or HIV infection. And this presupposes that some of the prices for drugs used in this disease -- that is AZT, pentamidine -- have really been marketed, to use Senator Kennedy's term in the bill that he put forward, unfairly. That's not my term.

Pentamidine as an example -- this was in our report for those of you who read it -- when it was granted orphan drug status went up from $25 a dose to $100 a dose, and that does not include the treatment cost of pentamidine, that's

just for the dose itself. So this would be an attempt to lower some of the costs of AIDS drugs.

The impact that it could have would be to generate savings for all payers who pay for these drugs at this point, and it could reduce probably most strongly the costs of early intervention. As we looked into what percentage of early intervention costs are drug costs, the State of New Jersey estimated that about 90 percent of their early intervention costs were for drugs.

It could improve efficiency of production of the drugs if there were price caps. The difficulty here is that each drug would have to be arbitrated between the government and the drug company, so that the negotiations could be complex, time consuming, expensive. The advantage here, of course, is that you would not be leaving to market forces, to competitive forces, the pricing of some of these drugs. And I just would cite the experience of the government with the WIC program, Women with Infant Children, as the major buyer of infant formula and the competitive bidding for the price of infant formula for WIC was left to the market, market forces, and there was extensive price fixing between the three major suppliers. So that the market forces actually

were not very effective in helping to reduce the price. So that's the price ceiling option.

The third option, which we just put forward --

COMMISSIONER KONIGSBERG: I just want to ask a with Option 8. Is there any precedent for specific price setting for pharmaceutical agents?

DR. BEYRER: What I was referring to with the WIC program -- I don't know if you want to consider infant formula a drug, but --

COMMISSIONER KONIGSBERG: Well, I'm pretty familiar with the WIC program and the concern over price fixing, and then they got into the rebate program it seems to me as a way to try to get at that.

DR. BEYRER: Right.

COMMISSIONER KONIGSBERG: But I wasn't aware that the prices were actually set by government, although the effect may have been the same.

DR. BEYRER: Right, it wouldn't be a direct.

The other precedent -- again, not an exact precedent -- would be the government buying of vaccines for some of the vaccine preventable diseases.

COMMISSIONER KONIGSBERG: Well, that's actually had

the opposite effect I expect. I mean, the price of vaccines once they became a monopoly, even though bought through government contract, have been really high. They have got maybe not a total monopoly, June.

CHAIRMAN OSBORN: No, I don't think so. I think what pushed the vaccine price up was the liability issue rather than anything else.

COMMISSIONER KONIGSBERG: Well it did, but my point is I'm not sure that -- I guess I'm really skeptical that this is the way to get at it. The orphan drug thing is a different story I think, although maybe the drug companies wouldn't see it that way. But just the setting the price is just almost a guaranteed mess somewhere I think.

CHAIRMAN OSBORN: Tim.

MR. WESTMORELAND: I have a couple of comments, but to be sensitive to your time maybe I should let you finish.

DR. BEYRER: No, go ahead.

MR. WESTMORELAND: I think the only setting I know of in the general public of precedent for price setting is in consolidated purchase of vaccines, and the price to the government actually has been substantially lower than the price to the private sector. There has been significant

price increase over the years, but the price to the government has stayed significantly below the private sector.

And the only other place I know of consolidated purchase like that that we have examples isn't really a cap but in some negotiated purchase both with the Veterans Administration and with some of the larger health maintenance organizations, and they in fact have been able to negotiate price reductions. Those of you who have followed the past six months of that effect though have noticed that they are all losing their price reductions because we have now required Medicaid to get the best rate that everybody else gets, and so rather than discounting the Medicaid rate, they have raised the price to the HMOs and to the Veterans Administration and everybody else. So it is a very complex issue of whether the drug companies would deal or not deal.

I also think that another example that might come to mind here is that AZT is a universal price in all countries right now. It is the only drug I know of that's that way, but even those nations that have had very successful programs of price caps and universal purchase of insurance are paying the same cost for AZT that we are. So it would be a very hard nut to crack I think on this.

Why don't I save my orphan drug comments until later.

CHAIRMAN OSBORN: Diane and Harlon and Don, do you want to go ahead or do you want to hear the third option and then we can -- I would assume that these are all fairly closely related. Perhaps if you want to finish off and then let everybody have at it.

DR. BEYRER: Okay. The third would be to have the government buy at a negotiated price and then offer the drugs, either with a means test or an asset test, and be basically the supplier and try and use the leverage of being a single buyer.

CHAIRMAN OSBORN: Diane.

COMMISSIONER AHRENS: Well, maybe my questions were answered. First of all, I wanted to know what other countries were doing with respect to this drug issue, and Tim has talked about AZT, but maybe there are other ways that we ought to get at this problem from the base of the problem rather than reaction to what is. That was my first question.

And then, obviously, your third recommendation here of having the government buy it at negotiated prices maybe a solution to this issue. I guess my question is going to be

what kind of recommendation do you think this Commission should make to the Congress to get at this issue? I think some of us feel very strongly about this issue, and what can we do as a Commission to make these more available?

DR. BEYRER: I would say -- I mean, it is clear that as some of the newer agents are being licensed that they are all being licensed in this very high price range. Fluconazole is another example of a recently approved drug that is probably more costly as prophylaxis than pentamidine. And how to go about that in a for-profit system where drug companies are insisting that they are covering research costs is difficult.

One way I think would be to have the government be a single buyer and then to distribute basically by need so that people would have access to treatment. That, of course, is going to be expensive at the prices that drugs are at; if the drug companies are willing, if they can be approached in terms of finding a medium ground, a lower ground of pricing. Because, of course, as it stands, a lot of people simply can't afford these drugs and don't get them. And I'm sure you have all seen the tremendous advertising that is going on, backed by Burroughs-Wellcome, of get tested for HIV.

They have full page ads in the Times everyday about, you know, my life changed for the better since I got tested, et cetera.

So they are trying to encourage people to get tested and get into early intervention. Their market could only improve by having a government-sponsored program where people could get the drugs. So that may be one answer.

CHAIRMAN OSBORN: Harlon was next, and then Don and then Tim and then Charley.

COMMISSIONER DALTON: I'm not sure I understand your Option 8, the price ceiling. Who would be setting the ceiling how?

DR. BEYRER: Well, for example, you have -- to take pentamidine, as probably the easiest example to address your question with, because we have a price -- pentamidine has been around for awhile. It was used for some parasitic infections. So its price before it was granted use in PCP prophylaxis and before it was granted orphan drug status was $25 a dose. So even if we said look, the government can negotiate and say --

COMMISSIONER DALTON: No, my question is who is the "we"? Are you talking about the government negotiating

prices with drug companies who then agree out of the goodness of their heart? Are you talking about legislation?

I'm just trying to understand what the mechanism is. I understand perfectly well with respect to pentamidine how one might arrive at a price and justify it, but --

DR. BEYRER: I think it would probably have to be federal legislation. I don't think that there would be another way to do it.

COMMISSIONER DALTON: But if it were federal legislation, then why would there be complex negotiations with producers and individual arbitration? That's what is confusing me.

DR. BEYRER: Well, perhaps what I meant by that option was that each drug would have to be individually addressed and the pricing of each drug would have to be individually addressed, and I think you would have to look into what is fair for each one and what would be a fair price. That's what I'm discussing in terms of being complex. In other words, you would have to do it for pentamidine and AZT and Fluconazole.

COMMISSIONER GOLDMAN: I have this image of this drug rate setting commission and another public utilities

commission kind of structure to determine rates for drugs and dealing with, you know, what are the allowable costs and going through a whole process of creating a bureaucracy, and, I mean, I wonder whether or not that's really something that is politically practical of turning the pharmaceutical industry into a public utility, and whether or not that makes any sense to do either, and what even the transaction costs for setting up such a system would be and whether or not that might even -- how that would weigh against whatever cost savings might be effected.

I don't really know. Those are just some thoughts that come to mind that suggest that that might be a lot more complicated than -- I mean, setting a price might be a lot more complicated than it looks.

DR. BEYRER: Well, I think that that's a realistic perspective. At the same time, there is a consensus that, you know, we are struggling with some of these different options to find ways to get money for early intervention, to get money for Medicaid programs. And, you know, when you think that close to 90 percent of early intervention costs are going into these drugs, it is a very real part of the problem, and addressing it and figuring out a way to cost

these drugs out. And it is something that the HIV community, the AIDS community is acutely aware of.

I mean, people are following the stock of some of these companies very closely, the profits of these companies, and -- I mean, I think from an ethical perspective it is quite extraordinary that we are not supplying people with drugs that can prevent them from getting sick, and this is adding to costs in a lot of other directions. I mean, if people don't get prophylaxed for PCP, they end up in emergency rooms getting that care.

So this has implications in a lot of directions, and these costs are -- I mean, they are quite extreme. None of these drugs are inexpensive. And there is some precedent with AZT. As you probably know, the initial marketing was at $8,000 a year, and they lowered the price of a tablet of AZT 20 percent because of outside pressure to $6,000 a year. Now it is less than that because of the dosing.

CHAIRMAN OSBORN: Tim next.

MR. WESTMORELAND: Yes. I don't want it ever to be suggested that I am an apologist for the pharmaceutical industry and its pricing structures, but I have to disagree with a couple of the suggestions that are made here. And I

say that full well knowing that you are quite correct, that there is a lot of enrichment going on, that the pharmaceutical industry stocks have out performed Standard and Poor's every year for the last 25 years and that there is a very good reason for that. But I'm afraid in some of these suggestions about killing the goose that lays golden eggs. While I don't believe that the pricing structure is fair and equitable, it has in some instances produced some pharmaceutical breakthroughs that we haven't gotten through other means.

I'm particularly concerned at your suggestion that we delete all Orphan Drug Act coverage for all AIDS and HIV drugs, because while I think that for some of the larger markets like basic anti-virals, or maybe even for pentamidine where you can look and see that a lot of people are going to use it for some of the rarer opportunistic infections and neoplasms, I think we are going to need some of the tax incentives and exclusivity and things like that to get anybody interested in a market that small. And I think that we need to be very careful that for some of these conditions we are going to need all the incentives we can get to get people to come into this industry. And so I think that this

is written a little large right now and reaches a little too far.

The other thing that I want to make clear is that the amendments passed last year and that got vetoed essentially only fixed a glitch in the law in the AIDS and HIV area. They didn't have a real substantial policy change. The premise of the Orphan Drug Act is that any market of 200,000 people or more is self-sustaining, that there can be competition in it without driving people out of the business. The glitch in the law is that you have to be 200,000 or more at the time you apply for the drug status, not at any time during the seven years. And that's all we were trying to fix, and if you fix that to say the Commissioner of Food and Drugs can look any time in the seven years of exclusivity, pentamidine takes care of itself, because there are now more than 200,000 people who need pentamidine.

So I just don't want to kill the Orphan Drug Act when I think it is going to be a valuable tool for us later on. And even if that doesn't fix and even if the President continues to veto that fixing the glitch in the law, I'm pretty hopeful -- and you would know this better than I -- that some of the newer developments in PCP prophylaxis will

actually make the market competitive again, not in aerosol pentamidine but because bactrim and Septra and Dapsone and those other drugs which are available at a very reasonable cost will drive a lot of physicians and a lot of patients into other kinds of drugs and have de facto competition for the same indication. And so I'm hopeful that we can do that, and I just don't want to damage the Orphan Drug Act along the way.

The other thing for the consolidated purchase and the price ceilings, I just want to inject I think the note of realism that Don was talking about here to, that you shouldn't underestimate the pharmaceutical industry's power and opposition to something like this, that the PMA and other drug manufacturers almost defeated the catastrophic provision to add prescription drug coverage to Medicare even though they were clearly going to make a billion dollars a year on it because they thought it was the camel's nose under the tent to get to price controls in the Medicare program and that Medicare would be such a big purchaser of prescription drugs that federal prices would mean that they couldn't set prices for Blue Cross or Blue Shield any more. And they were willing to give up a billion dollars of federal money to do

it.

So if they are not getting much from us, and we don't have very much money to bargain with, I think we can anticipate that they would come at us hammer and tong and say pay for everything but AIDS drugs in every program so that we don't have to deal with this pricing.

And the final thing that I would say is I think, going back to your original problem that I think that you have nailed real well here, is I think in many ways what we are seeing with a lot of these prophylactic drugs and these outpatient treatment drugs is the pharmaceutical industry has finally wakened up -- maybe before we have -- to the fact that the real cost comparison here is not between this drug or that drug but in Fluconazole and pentamidine and things like that it is this drug versus a day in the hospital, and that every private insured patient will get a drug because it is always going to be slightly cheaper than putting them in the hospital, and that all those driving forces I was talking about this morning about how people cost things out show that drug manufacturers, as long as they stayed just under the price of hospitalizing somebody for pneumonia, will still be able to get reimbursed for these outlandish costs because it

will be better than actually putting them in the bed.

CHAIRMAN OSBORN: Charley, Phil Lee, Harlon and Diane.

COMMISSIONER KONIGSBERG: I want to talk a little bit more about the notion of government contract for HIV drugs. In many ways, and June is correct, the effect that that had on childhood vaccines, but it depends on where you look. From a direct budgetary perspective, at least in my state, and I don't think we are alone on this, it actually had the effect of kind of increasing what we have had to spend. Because what we have had is a shift of immunizations from private sector to public, and for obvious reasons, if the vaccines are three times as expensive out there. And I would submit that you can extrapolate this kind of a problem to the HIV situation. Where there is already a tendency not to take care of these patients, this could be one more incentive.

I think it is a good idea, however, as a technique provided there is a way to make sure that the public sector doesn't wind up not only buying the vaccine -- let's just say the Kansas Department of Health buys all the HIV drugs on government contract, because that's what would happen. We

also could wind up then finding out the only people we could distribute it to are local health departments and community health centers and we haven't done anything about getting it into the private sector, which is a problem with childhood immunization. So while it is a good idea, it needs to be explored as to how it would fit into the concept of mainstreaming early intervention as well as the care of AIDS. That can probably be done, but it hasn't been done with vaccines in my opinion.

DR. LEE: I'd like to really strongly associate myself with Tim's comments. The Orphan Drug Act is very, very important and I think if you asked Tim and maybe Bill Core to help you craft language for whatever your recommendation is, you would take care of the pentamidine issue without undermining the very great benefits of the Orphan Drug Act with respect to the kind of R&D that needs to be done around many drugs with respect to AIDS.

On the pricing question, clearly the government has set prices for hospital payments in the Medicare program. They have recently set prices for physician payments in the Medicare program. So that as a principle the federal government isn't afraid -- I mean, it was the Reagan

administration that set prices for hospitals and the Bush administration that set them for physicians. So that as a principle, that sort of anti-competitive, if you will, regulatory approach is one that at least in these two instances the administration has been very willing to support. But because Medicare isn't a purchaser, and we have seen what happened with Medicaid with Senator Pryor's effort, simply raising the price to everybody else, the government has the authority now to be a purchaser.

And it could in fact purchase in Europe, if necessary -- in Italy or Germany -- where prices are significantly lower because there are caps on the prices in France, more recently in Germany. But I myself think that this Commission is not the proper body to consider that issue. No question it is a problem, you can identify it as a problem, but you do not have -- I mean, I have been involved in this issue for 24 years and the industry did make -- I mean the drug industry played a significant role in killing the Drug Commission and the catastrophic legislation. I think the elderly appeared to, but there were other forces at work.

And I think you don't want to tread on ground that

you do not have the expertise in this Commission, and I would simply identify the problem but simply acknowledge the lack of expertise both on the Commission and within the staff to deal with a very complicated issue. And you may lay out some options, but I even think there you are treading on very, very thin ice, because to really analyze the pricing issue with respect to drugs and then the impact on R&D, you get yourself in really hot water in a hurry.

COMMISSIONER ROGERS: Harlon.

COMMISSIONER DALTON: I must say I'm having great difficulty understanding the conversation. I understand with respect to the Orphan Drug Act what Tim and Phil Lee had to say. It seems to me that Option 7 even in its own terms, the justification for disallowing the application of the orphan drug law is that AIDS is no longer a rare disease, that there are enough numbers out there. And so certainly with respect to anti-virals and with respect to PCP prophylaxis, it seems to me that case could be made. Probably not with respect to drugs for other opportunistic infections. That I understand.

Other than that though, I'm not sure where we stand. I think we are being told that this is too complicated. We are being told that the pharmaceutical

industry is too strong. There is some suggestion that we ought not to interfere with the market, though I certainly don't find that compelling as a matter of ideology certainly, or economics. Maybe the people on the Commission don't have the expertise, but that, of course, is why we have asked for experts to come to us and help us figure out how to accomplish an end, which is exactly the one that you laid out, Dr. Beyrer, but you don't have to keep repeating it. There is no one around this table who believes that these live saving drugs can fairly be priced in the way that they are.

The question is what can be done to change that, and we need some help from somebody. It is not enough to say well we don't have the answer and our staff doesn't have the answer. We need your help, and if not your help, then we need someone's help. But if this Commission doesn't do it, who is going to do it? And the fact that the pharmaceutical industry is strong and powerful, that's fine, they will do what they have to do.

We need to take that into account but not in terms of, it seems to me, cutting, shaving our recommendations. But we need to take it into account because if there is an

approach that it is less likely to raise their collective back than another, then maybe we ought to tilt in that direction, but not simply walk away because the industry has an interest in fighting it.

COMMISSIONER ROGERS: Did you want to respond?

DR. BEYRER: Yes. Well, I certainly, you know, agree in principle with what you are saying and I'm glad to know that there is support for this idea of everybody here. I can tell you that in Maryland, the Maryland plan, which just recently was threatened and actually ended and then restored, was an AIDS drug assistance program where Maryland basically bought the drugs at the price that they are at in the open market and supplied them to anybody who didn't have access, including people who were waiting for Medicaid or medical assistance for that time to fill in the gap. So that if you wanted to write a prescription and people didn't have the money, you could get them on the drugs right away.

Now that's an immediate option that helps deal with the issue of access, but, of course, it doesn't do anything for the price of these drugs and it is expensive. And it, obviously, in that case was a purely state program, and I think we are clear that the states that are hard hit with

AIDS are not going to be able to afford to do that.

The possibility of the government buying the drugs as a single buyer and then providing them depending on need I think is one way to really use what leverage the government has in negotiating a price. That's in some ways different from a ceiling, and again would require bureaucratic outlay certainly.

I'm not sure that beyond -- well, maybe Tim you can address the issue of what other mechanisms aside from the government buying drugs and marketing them exists in other countries. I mean, one of the things that is going on, of course, is that people with AIDS are banding together and forming buyers clubs and buying them at cheaper prices abroad anyway and the FDA is just allowing that to happen. And there is bootleg DDC being made in this country and marketed at a much lower price than the government price.

So I think there are, you know, potentially dangerous solutions that are floating around in the patient community that this Commission is probably -- you know, it would be important to address.

CHAIRMAN OSBORN: I think we go next to Diane and then Tim and then Pat Franks.

COMMISSIONER AHRENS: I'm with Harlon, I think the issue of drug pricing is so obscene that I think we need to hit it hard. I think this Commission needs to hit it hard. And what I'm wondering is if we come at it not just from an AIDS orientation but from an orientation of chronic illness drugs and talk about either some sort of price ceiling -- we are putting ceilings on everything else -- let the pharmaceuticals do what they are going to do, but since it is not a part of Medicare, the drug business, I think you would have an awful lot of seniors out there that could be brought into the picture to feel strongly about this issue, and what it needs is a little bit of publicity. I think the public doesn't realize just how great the mark up is, what the cost of the drugs really are. I don't think the public is going to be very sympathetic to a mark up of 1,000 percent, or whatever it is, on any drug. And it needs to get a little bit of press, it needs to get a little bit of understanding. The public has to be educated, and particularly do senior groups have to be educated.

And we get a group like that on our side and we might cure quite a number of things. I think we need to be more, perhaps, inclusive in this area, more hard hitting, and

I think the public is really with us.

COMMISSIONER ROGERS: Let me just interject because I want to buy on with Harlon and Diane, but I have been struggling as to how does this Commission get out of the bind we are in, and here are my concerns. That this Commission, no matter how long we listen or debate, will never be viewed as the experts on the financing -- and one of the treats -- but Karen Davis and her group are, by both sides of the House and what have you, they have had 20 plus years of experience.

It seems to me, Harlon, what this group should be doing is precisely what you say, that there are things that are unacceptable or that we are dreadfully concerned about and that we need ways to fix it, but I don't think we need to go the next step. I have been sitting here struggling with how we could do that and make use of all the talent we have got, which I think would give us some credibility but without us making the very specific sorts of recommendations.

Let me just try this out on you. It seems to me it runs kind of like this, that statement kind of number one is that efforts to deliver swift and appropriate care to those with HIV infection and AIDS have made the gaps in the financing of health care for many Americans glaringly

evident. That because those who are HIV infected are often poor or from minority groups, a disproportionate number of them fall into that group of 36 or 38 million Americans or what have you that cannot pay for their health services -- craft it the way you wish. That this poses an enormous problem; that in the absence of ways to pay for primary services for care, all of the suggestions which this Commission makes about efforts to do better with those with HIV infected people fall far short of their mark, and that it will prove enormously expensive to this country if we ignore that.

Thus -- I'm just trying to work some way out of where we are that doesn't require us to do things that we are incapable of doing -- thus, the Commission believes that the nation should take aggressive efforts to move us toward a system which will cover the costs of basic health services for all Americans, that as an incremental step, for example, perhaps the first step is to assure that we have a financing system for those who have chronic or relapsing illnesses, which would include those with AIDS. That in an effort to get there we have before us, designed by Karen Davis and her associates, or what have you, a series of options on how this

might be approached. That the Commission would recommend some combination of one from column A, one from column Z, one from column Y. Why? Because in our judgment that covers -- that best -- one, that it might have the most consensus in terms of getting passed or, two, that it would cover the majority of people who are HIV infected.

Now, I'm content to go -- I think we need to explore, as we are, all of these different options, but I think for us to then try and say we should do it precisely this we, we wouldn't be creditable. But we could say here are a series, but here is what we want to come out of this, that it should cover as many as we can, it should receive public acceptance, and if you don't it is going to be a hundred-fold more expensive if we can't do that.

It seems to me we can get something like that that this Commission could come out saying, these are the ground rules, this is where we must be as a nation, and then put a series of options, or even elect from those as far as we can, but not try and go farther than that. Thems at least my thoughts at the moment on where we should come out.

DR. DAVIS: And I think, if I could respond, one thing that is missing from the draft and our presentation is

kind of a set of principles that the Commission might be willing to endorse, a set of criteria that they would bring to bear to looking at the solutions, and I think that kind of information, and then you could decide whether you want to go also a step further and say in particular these seem particularly promising. But I think that to kind of shape out of this discussion a set of principles that the Commission would be comfortable with, whether it's that drugs ought to be fairly priced, even though one doesn't go so far as to say "and the government is going to pass a law to set $25 as the maximum price for pentamidine" could be a stage. So I think that's a useful thought.

COMMISSIONER ROGERS: And this discussion seems to be moving us that direction in part in terms of establishing those principles, but it's these are the principles on which the Commission must stand and we feel intensely about these. And then here are as wise a group of options as we can give you and choose with these fundamental principles in mind that we feel strongly about, something like that.

COMMISSIONER DALTON: I just want to say, David, I have been trying in a way with each of these options in my own head to convert it into a principle so that we don't have

to get to a particular level of detail. I think there are some principles that emerge from these drug options, for example. And so I would be very appreciative if, Karen, you would, at least as the first proposition, do the work for us and distill the principles. In fact, I have animated you all in making these choices. And at some point we may want to go further and give some examples, but that will take us another step down I think, which I feel somewhat uncomfortable having the choice of either real abstraction or real detail.

CHAIRMAN OSBORN: We have got Tim, Pat, Phil Lee, Jim Allen.

MR. WESTMORELAND: My comments are probably not responsive to David's now, but I do want to defend my record on one point. I do not want to be heard to say be shy of criticizing the pharmaceutical industry and its pricing policies. I think you should have the bitterest criticism you could on behalf of these populations. And I didn't mean at all to be heard to say just because they are a powerful lobby you shouldn't make any recommendations about it.

But now, being responsive to the conversation that Dr. Rogers has started here, I would also lay out for you one of the things that I see happening within the financing

systems that I work with, which is that the pressing and painful and very visible needs for immediate care of the acutely and intensely ill has prevented this system from being able to plan on how to keep the asymptomatic asymptomatic and how to keep minor ill minor ill. And that's not unique to this system for AIDS by any means, but I think that it is something that if you are going for general principles I would put on the table, that one that this system seems to overlook all the time is that we concentrate on the disasters of people who have to be hospitalized now and we don't do much to keep them out of the hospital.

MS. FRANKS: I guess what I would like to add is that equity is a principle, and to me talking about changing the reporting ceilings on prices for drugs for persons with HIV infection is totally unacceptable as a group of people, that we have elders and we have all kinds of folks who depend on drugs, and to make that change for one group of people is not acceptable.

CHAIRMAN OSBORN: I think that that was probably starting principles at the beginning of the day, which, just to simply the conversation, I think that's one that we all rather accepted at the beginning, but thank you.

DR. LEE: Again, to go back to the principles, it seems to me there are two with respect to drugs. One is you want them available and you want them affordable. And then you can be very critical of the current competitive system with respect to some of these drugs. They haven't been available because they are not affordable, and if the market doesn't function well enough, then the government needs to consider, one, government purchase, possibly price controls of some sort. I mean, it seems to me that you take steps in order to achieve your goals, but I think those are the two that you really want to define at the level of principle.

MR. JIM ALLEN: David, I like your approach to the morass of the health care financing and what I think this Commission credibly can do in terms of moving the argument forward. It seems to me you twice in your statement hit upon the fact that to not move towards this kind of a solution is going to cost us more in the long run. I think there are an awful lot of people out there who don't believe that, and part of the argument that needs to be built into in this, it seems to me, along with the principles are some very solid examples of how failing to take the steps that need to be taken are going to wind up financially affecting us. Too

often I hear we can't do it because we can't afford it, and we all know that we can't afford not to.

But I think we have got to be able to prove that point, and I think that some of our consultants could give us the material that would help set forward that kind of an argument.

CHAIRMAN OSBORN: Diane.

COMMISSIONER AHRENS: David, what you are saying has a lot of merit to me.

COMMISSIONER ROGERS: Thank you, Diane.

[Laughter.]

COMMISSIONER AHRENS: I better stop here. But. Oh, David, I've set you up. Now you have made me forget my train of thought. You are so disarming.

So often commissions such as ours come out with sort of broad-based wonderful principles and criteria and nothing happens. I mean, people expect the broad base and they expect the criteria, and they expect it to be nice and reasonable and rational, and nothing happens. So if there is a way we can do this to make it compelling and specific enough so that -- and Tim left the room because I was aiming this at him, -- but what does the Congress need from us to

move us along here? How specific do we need to get to get them to at least take a look at things and maybe draft some legislation?

I guess that's my question. And I really loved what Phil said in terms of his comments about the drug issue. I mean, come at it some in such a way that what we have got folks is really unacceptable, and all that nice verbiage, and them some specifics, but maybe not too specific, that kind of coming at something.

But it is a question, and I wish Tim were here, but someone can address it in terms of what does the Congress need from us?

DR. DAVIS: Well, I would toss one specific back to you. Again, I think I would be comfortable with principles, but you may -- I was seeing it as a prelude and a context in which you would make recommendations, which you may decide to stop short of. But I guess one specific I would just toss up was specifically fixing this glitch and whether the Commission wants to at least go that step of saying that if it reaches the threshold of 200,000, or whatever, then it shouldn't be subject to orphan drug protection, never mind that it didn't have that level when it was first started. So

that would be a very concrete suggestion that certainly at least had the support to get it through Congress as a bill, and would the Commission be comfortable with that step but not yet into the heavy hand of price regulation?

And then do some of the things that Phil has talked about about critiquing how poorly the current system is working to really make this available in an affordable way.

We could use that as an example of whether you see just the principle available and affordable or whether plus fix that one glitch at least in the orphan drug law.

CHAIRMAN OSBORN: I think that's the sort of thing that we can probably easily do, and I think David was talking a little bit more about the specific mandated fix that one figures out for things. And we can point to some fairly glaring things that the fixing of which doesn't solve the problem but does also help to highlight it, and that one is a particular good example since it got all the way to a pocket veto, so it is not so difficult. And I think -- well, I don't like to take the floor -- I do want to speak up about the Orphan Drug Act, because I want to point out to the Commission that we have gone on record about the need to be making much more progress on opportunistic infections. We

didn't mean PCP when we said that, and virtually all the rest of the progress is going to be in part dependent on the Orphan Drug Act's integrity in order to do that.

So I think both from Tim's -- he is commenting from one point of view, but I would comment from the scientific point of view that that's a pretty important area to keep viable and that the Orphan Drug Act is one of the few things that keeps it viable when we get to the minor, but for any individual very important, infections that prompted us to make our recommendation in our third report.

Don Goldman, Phil Lee and Molly.

COMMISSIONER GOLDMAN: Yes, I just -- two entirely separate points -- but one of them is that I distributed earlier a memo that I wrote that is more directed towards our conversation tomorrow. But one of the points that I tried to make in that memo was the interrelatedness of care, research, and prevention as well. And I think one way of looking at it, sometimes the most effective way of bringing the price of a drug down is to invest money and research in other drugs, and that we really ought not lose sight of that, that that may in certain cases be the most effective and most cost effective way of dealing with the topic.

And that, of course, runs the added benefit of getting a better product, but once there is competition out there in the market, even if it is another drug or an analogue, or even if it deals with it slightly differently, very often that can be the way in which prices can be reduced. And certainly I think it is better for the community to invest the resources toward that ends than it is toward elaborate bureaucratic systems which would set prices and in what way.

Which leads me to the next perspective, and that is the one area in which I suppose I have some attempt at trying to acquire knowledge and experience, and it is mentioned in the report, although it is not referenced in any recommendations, are the prices of clotting factor for persons with hemophilia, which make the cost of AZT look like a pimple. I mean, we are talking about $100,000 a year, not $5,000 or $10,000 a year. And yet I know in dealing with those areas that in many instances much of the price is in fact probably justified in terms of some of the research costs, as well as all of the risks involved in terms of, you know, what have kind of time period do you write off research costs if there is going to be another substitute drug on the

market or replacement. I mean, right now we have some of the expensive drugs that are sitting there now for treating hemophilia and we have pending an FDA approval for products produced by recombinant technology, which I suppose make those that are producing the clotting factor manufactured through plasma worried about how long of a lifespan their particular drug has and how long do they have to depreciate or write off their research costs.

People are starting to talk about, at least in that area, a second generation of recombinant product which involves only utilizing a smaller portion of the molecule rather than the entire molecule. That leaves a question as to all of the investment in terms of that area, how long do they have to write it off. It is a very, very complicated area to get involved in in trying to regulate the pricing of drugs and which costs do you allow and which ones you don't and things of that nature. And I would rather see money spent in terms of research rather than bureaucracies to try to control prices.

DR. BEYRER: I think that's a fair comment, and certainly I am a supporter of research. However, I would just add that if the end the products of that research are

priced at the same level, then you really haven't helped that many people, and I think we have to be aware of that problem. Certainly as far as the hemophilia, the cost of those drugs, as you probably know, at lot of that is because of the need to treat for many different viruses and to get viral-free clotting factors. And, of course, it is a much smaller population. There are 20,000 hemophiliacs in America, but we have seen cost figures as high as $300,000 I think for one round of a bleeding episode. It is a huge problem.

CHAIRMAN OSBORN: Phil.

DR. LEE: A couple of things. One, on the research side, I think it would be important to look at the licensing policies of NIH particularly, and I think there are some people who feel that NIH basically gave AZT away by giving an exclusive license to Burroughs-Wellcome, and that that could have been handled much more. And when you have federal funds involved in the research, then of course the patent does belong with the federal government and they can license the drug, so that's an area where there might be more competition stimulated.

Second, the Senate Finance Committee is very concerned about what the drug companies have done with

respect to Medicaid. Senator Pryor, unfortunately, has had a heart attack, but I think his staff, I think that Senator Chaffee's staff, and others have been looking for information in this area. And the one place where there is information, of course, is in Europe. In France, Germany and England they have all taken somewhat different approaches to controlling drug prices, and there are people there who are knowledgeable. When I get back to San Francisco I can actually look up the names of a few people who would be -- if you are interested in pursuing that matter downstream as a way of saying we are serious about this, as we go forward we are going to investigate these other areas more thoroughly. Canada also has used I think some interesting mechanisms to control expenditures for drugs, particularly in long-term care and particularly for the elderly. And I think British Columbia particularly has had some interesting approaches there that might be worth looking at.

CHAIRMAN OSBORN: Molly.

DR. COYE: I think that the point that Jim Allen brought up a while ago, and Diane talked to too, about the need to address the cost effectiveness of early intervention and to try and deal with this in the context of the fiscal

analysis or the proposals for reimbursement strategies is very important. It needs to be confronted. I'm not sure what the answers are. I certainly don't have a lot of expertise in this area. I think that if the Commission is working towards an analogy to other chronic diseases it is important to put it in the context of work on diabetes and other chronic diseases so that where it is analogous it can be made clear and where it is not analogous the differences can be made clear to people to help people think about this issue, because it is not something a lot of us are very sophisticated about.

But I think that would be very helpful and I think it should include Tim's point that look, there are going to be large areas whether either we don't know whether something is cost effective, especially over a many year length and lifespan and that there are probably significant ways in which we are going to incur greater costs by doing what is right clinically, and that people have done that in other areas of chronic disease cost effectiveness analysis and it needs to be applied here. But I think it would be a big service to the readers of the Commission's report to have some elucidation of how to think about these issues in a way

that would be clear. Another easy task.

CHAIRMAN OSBORN: Harlon.

COMMISSIONER DALTON: My hand went up awhile ago because as we were responding to David's question about the level at which to pitch our report with respect to health care finance, I found myself wishing that Irwin and Mike would speak to it since between them, or even individually, they have a fair amount of accumulated wisdom and I always benefit whenever I hear them, so that's why my hand went up, guys.

CHAIRMAN OSBORN: You have just been nominated.

DR. DAVIS: I think I'm going to have to excuse Dr. Beyrer, but I appreciate a lot of these comments and we will take that point and try to draft this again.

CHAIRMAN OSBORN: Dr. Beyrer, thank you very much. We appreciate it.

Goodness, you have just been given the floor and you are going to sit back like that?

MR. PERNICK: Let me comment later.

CHAIRMAN OSBORN: Okay.

DR. DAVIS: Well maybe we could move on to some of the other options and then come back to a summary discussion

of where we go with this and what is the Commission most comfortable with. The other option we did want to talk about is kind of targeted funding for providers, and to back up one to Chart 21 and Option 6.

DR. CHAULK: This is Option 6, which talks about providing increased federal funding targeted for areas that have a high prevalence of AIDS cases, particularly a disproportionate share of cases, and this, of course, is the Ryan White Act. We feel this option has benefits because it would hopefully reach most of the hospitals and health centers which provide a significant amount of care to the greatest number of HIV and AIDS patients. By doing this, since many of them are public and teaching hospitals, it would take off some of the burden from these hospitals which already deal with other indigent care issues as well, and by providing this funding, of course, it would be possible to deal with these other indigent and uninsured patients much easier.

I guess one of the other benefits of this is that we moved right in to targeting disproportionate share areas and going around what has already been discussed as an almost labyrinthian state-by-state Medicaid approach to dealing with

this, and this is certainly one way to short-circuit that approach. It helps us avoid some of the waiting periods on Medicare as well.

In terms of costs, I guess one key feature here will be the extent that you do want to or do not want to include drugs. That obviously would concern the outpatient care substantially in the clinics, which is where, as has already been mentioned, a significant amount of the cost occurs for drug therapy.

If, however, drugs are covered, then again you would avoid the Medicaid plans that may vary from state to state as to whichever drugs they are covering, and you would not deal with populations being given limited access to certain types of therapies.

A down side, of course, is the degree to which it its funded, and, you know, we have seen now that the funding is somewhere around 240 million, which basically is probably doing nothing more than providing funds to care for people who are in the system now. It is not really opening up access to care, and I think there is clearly a feeling here that that is one of the concerns of the Commission, is broadening the access issue, and unless funds are

substantial, at least beyond where they are now, then that issue will not be addressed.

I think in terms of controlling costs, the more that outpatient services can be kind of featured and preventive services featured and innovative programs featured, such as through the Title III and the Title IV sections of this act, that those novel strategies for bringing together, as Dr. Coye mentioned earlier, trying to coordinate substance abuse and trying to coordinate these different systems to really provide the coordinated care that these very complex cases need, a lot of that is going to be done through novel projects, and I think that that's going to be something that really needs to be considered in terms of funding, not just reimbursement to hospitals. Again unless the money is sizable, we are not going to deal with the access issue, and I suspect that's a very substantial concern of this group.

In terms of what it is going to cost, I'm much less comfortable with the numbers I have on the paper here. It was quite difficult to get dollar amounts for what is the amount of uncompensated care for hospitals providing care for HIV and AIDS patients. It was mostly drawn from Ann Drulis'

survey of hospitals in '89, and, of course, you know that is a small subset of the hospitals. I think 240 participated in the survey out of the roughly 5,000 hospitals. But given that limitation and given the fact that we adjusted a little bit for not everyone being a disproportionate share provider, we came up with a figure of roughly $600 million for hospital inpatient and outpatient care both, and the $1.3 billion is based upon the cost of care provided by migrants and community health centers, adjusted for the fact that they provide -- about 50 percent of their people coming through centers are uninsured, so that's where that figure comes from.

These are low end figure I would suspect, because as the community health center people told me, they are not screening enough people and getting in early to find out exactly what the HIV case load is in the clinics. And, of course, the other study again was a very small sample. However, we are hoping to get some more data over the next week or two to give us a better feel for this mix of public/private share of the care, which is very hard to pin down at this time.

And I guess on the bottom line this in a way is

kind of a band aid to what the problem is because it doesn't really change the system. We are basically going in and trying to argument a relief, which is what is obviously needed in this case, but the underlying problem of getting access and preventive care and primary care to people is -- this will not answer that over the long course, this is sort of the immediate response to the needs of the great burden of uncared for people at this point in time. That doesn't mean it doesn't need to be done, but this in and of itself is probably not sufficient.

And, of course, the final cost may depend on what you choose in terms of options. If you choose to adjust Medicare and Medicaid, you may not have as great a cost here if this is obviously your only option. So the degree to which you blend options together would be sort of the final dollar amount on this one. So I apologize for not having harder numbers here in terms of costs, but we will continue to struggle with that.

COMMISSIONER DIAZ: Of the options that you have outlined today, this one seemed to have the least possibilities for emphasizing the preventive and ongoing continuum of care, early intervention, and I'd glad you said

that because that was going to be my comment.

I wondered if really when we look at this model all we are doing is perpetuating the fact that some people may need and may continue to use public hospitals and the inpatient base system for continued care, but is that really what it should be? I mean, is that a good model to perpetuate in the management of HIV and the spectrum of HIV needs?

I personally do not feel that that is the most cost effective model, and other than the systems that you mentioned -- your 329 and 330 funded projects -- where this kind of care can be integrated into the provision of primary care and has the linkages with inpatient facilities and back into the community, really hospital based management of this epidemic is going to be expensive in the long run. I just would think it has the least possibility of emphasizing the preventive and early intervention package.

DR. CHAULK: I guess also, in that respect, in terms of quality and continuity of care as well. If your main source of care is the emergency room it is just not going to be what you want it to be, you are absolutely right.

DR. COYE: I just wanted to say that I think that

uncompensated care can include such a wide range of kinds of services being provided that some of it may escape from the umbrella that you are correctly putting over most of it, Eunice, that reimbursement for uncompensated care can be manipulated like any other system of reimbursement. You could, for example, not reimburse for acute care, you could reimburse only for primary care. You can describe the kind of primary care or continuum of services that you will reimburse for, and that has actually been done under uncompensated care systems for prenatal care and for other -- and actually in New Jersey we did it for the case management of early intervention.

So in fact while the nature of the way services are provided now, if you just say we'll reimburse you for them, will result exactly as you are describing it. If the choice were made, for example, not to go with any of the Medicaid options because of state objections or that that wasn't politically feasible and that it was federal monies, one option is a Medicare kind of option.

Another option is federal money to providers under some guise like a redirection or refinement of Ryan White. I'm not advocating that necessarily, but I think in terms of

a description of the full range of options you actually could envision money flowing only to providers that are community based or primary care providers that provide a continuum of services. And in our prenatal care program they had to actually be certified by the state on an annual basis that they were capable of and were providing and could document providing the full range of services.

So I think ultimately you could use it as a tool; it may not turn out to be the one that would be most effective.

CHAIRMAN OSBORN: Diane.

COMMISSIONER AHRENS: I'm glad David isn't here because I'm going to get to a level that he wouldn't like. But I'd like to ask --

COMMISSIONER GOLDMAN: He's coming in.

COMMISSIONER AHRENS: Oh, dear. I'd like to ask whether -- and I'm sure I'm going to attract a host of arrows -- the issue of contracting -- let me explain sort of what I mean by that.

I happen to be associated with a hospital that has a contract for providing all of the general assistance medical care services, both primary, hospital, et cetera, for

all of those eligible in our county. That means they do case management. That means that we put a per diem on every one of those people -- I shouldn't say a per diem, it's a per capita annual -- and then discounted it by 10 percent. That way it is cheaper for the public sector and it provides a good source for the hospital. It happens to be a very good hospital. They case manage that. It doesn't exclude community clinics because these people can go to community clinics and are reimbursed through the hospital mechanism and through that per capita.

Now, realizing that we need to talk about primary care, realizing that these populations will increasingly be concentrated in certain areas, has there been any thought given to this concept even in terms of pilot projects for certain states where this sort of thing might be manageable? You might not just deal with one provider or one hospital, because there are all kinds of associations and coalitions of hospitals that might be willing to bid in on this as a group in an urban area, but say we will do the case management, we will provide all the services, and through a variety of funding sources that would have to be pooled, I think we would have to use every available source that was out there

that was being used heretofore to put in the pot to pay for that.

But the other isn't working and this would -- you wouldn't have a free choice of vendor, you would be taking that away, but it has been taken away in other areas anyway, and provide that kind of focused care. Has that been considered?

DR. DAVIS: You know, the analogy -- maybe I'm not quite understanding it -- seems a little bit to the California approach with their Medi-Cal program of finding a hospital in a county, for example, which would provide care to the Medicaid patients the cheapest and then contracting with that hospital for all care. So sometimes it is called the prudent buyers approach or competitive bidding. So that's certainly an approach, that instead of targeting say under a Ryan White Act with expanded funding, that you would simply provided funds to any hospital, any clinic, any provider providing care to patients. You would say what are the rates at which you are willing to provide comprehensive services, and take a low bidder, or a low bidder with quality care or with a good track record. Whatever criteria it is, it is an approach that it is a little bit different than what

is laid out up here where I think there is more of an assumption whoever they went to and provided the services, you would try to give them some funds directly to offset the bad debts associated with providing that care.

CHAIRMAN OSBORN: Don Goldman.

COMMISSIONER GOLDMAN: I'm just wondering did the cost numbers here that you are talking about, for example, here $600 million for hospital inpatient area, I'm trying to figure out how that correlates, if it does, with the other numbers that we were using before in terms of Medicare. If we are talking about, for example, 2.1 billion for Medicare and most of that is covering inpatient costs because Medicare doesn't cover drugs and things of that nature, I'm trying -- I mean, somehow I'm not sure whether or not these numbers tend to all jive together or whether they do or not. I mean, I don't --

DR. CHAULK: I think that is a very good point and I think it reflects the degree to which this underestimates how much it is going to be caring for. I think that is really what it does, because it is really based upon that small sample of those hospitals and would have to underestimate I think. The degree to which it does I don't

know, but clearly you are right.

COMMISSIONER GOLDMAN: But then does that small sample -- assuming it's not an underestimation, does that mean that the other cost estimates are an overestimation?

DR. DAVIS: We hope.

MS. CHU: For the Medicare costs, some of those people were insured before under employer plans or Medicaid, so it is not, you know, an additional cost really to the whole system.

CHAIRMAN OSBORN: Harvey.

DR. MAKADON: Just two points. One is I think, you know, the Ryan White funds are just being distributed and I think before we kind of label this as where the funds are going to go to hospitals and health centers, we should really evaluate that and kind of have a sense of where the money has gone. This makes it seem as if it is a program targeted for hospitals and health centers, and I think it might be somewhat broader than that. And, in fact, hospitals may not get very much from it at all. So when I saw that, I think that needs to be a question.

The other thing is I think although it may be nice to think about novel demonstrations coming out of Title III

and Title IV, I would hope that the Commission would urge us to get beyond demonstration projects and thinking about setting up good primary care models that are well funded as a way of doing some of the things which heretofore only demonstration projects have been able to do. And I think the example of combining drug treatment and primary care is a good example. I mean, that's something which has been looked at in a couple of places, and a good primary care center should be able to do that with existing funding streams instead of always looking to write a grant application in order to be a demonstration project in order to do that.

So I think that one of the limitations of this is that it kind of preserves our thinking about innovative things as demonstration projects, whereas I would like to think that primary care in the broadest sense could do a lot of the things that are necessary not just for people with AIDS and HIV infection but for people with chronic diseases, if the funding really recognized the potential of what we can do.

CHAIRMAN OSBORN: Tim.

MR. WESTMORELAND: Just a point of clarification. I think Harvey is right, under the terms of the current Ryan

White law as opposed to some of the things that are outlined here, which I don't think are incompatible with it, under the current Ryan White it is against the statute in fact to use the money for hospital inpatient care, it is only an allowable expense for outpatient services and ambulatory services. So I don't think these proposals are contradictory to that, but I don't think it could be funded under the current law.

DR. DAVIS: So it is a legislative change and not just an appropriation change, so I think it would be also an issue if the Commission were interested in this option whether you want to see targeted funds going for inpatient care or whether you would like to see them restricted to go for ambulatory care, again recognizing that it is hard to ever get appropriations to a level that really begins to meet the needs.

DR. LEE: Just on that point, Karen, I think the ambulatory area is the one that is the most seriously underfunded by all the other third party payers, and so to me in the short term at least it makes more sense to adequately fund the ambulatory approaches as opposed to augmenting inpatient, which is just a -- well, it's at least more

adequately funded than ambulatory.

DR. DAVIS: Why don't I just wrap up with the last option which you find on Chart 24 and which we have already discussed a little bit today. Not knowing how far the Commission would feel comfortable, this one I even couched as "in principle" rather than recommending anything very specific. And as it reads it says "Support in principle expansion of health insurance coverage to cover the entire U.S. population through a combination of public and/or private employer-based health insurance coverage."

Under this option you would deal with the problems of the 34 million uninsured Americans. It is a comprehensive approach to health financing, not only because it is not restricted to persons with HIV or AIDS, but also it is not restricted to the poor, as the Medicaid options are; it is not restricted to the chronologically ill or the disabled, as the Medicare options are. In fact, it would apply to the entire population.

We could go through a lengthy discussion of the pros and cons of this particular approach. I think, again, what I see as the major con is that action doesn't seem to be very close in terms of any type of consensus at the public

level among the policy official level about exactly which approach to go.

In terms of costs, that may seem like a wide range and I'm really talking about very different proposals. The Pepper plan would require employers to either purchase -- certainly larger employers are required and smaller employers have very strong incentives -- to provide health insurance to their workers and dependents, and that they purchase that privately or have the option of having it done through the public system by contributing to the public system.

In addition, it covers then other people who are outside the work force under a new public plan with subsidies for anyone -- complete subsidies for anybody below the poverty level, sliding scale subsidies up to twice the poverty level. It is those subsidies for the low income that cost the federal government in its budget $24 billion.

Now, the Pepper Commission also had a set of recommendations that had to do with home care, nursing home care. Those add another 40 to $45 billion, so if you are talking both about acute care and long-term care, they are more on the order of a $70 billion federal budgetary impact.

The Pepper Commission also included some cost

estimates of what would happen to the federal budget if instead of having employers buying private insurance you had coverage of everyone under a single public plan, and that would be $225 billion of public outlays, federal government outlays, but that's because it displaces 200 billion that is now flowing through private insurance, employer/employee contributions. So it is not new money but it is new federal budget, it shows up on the federal budget as new money.

If you instead look at the total health system cost, we are actually talking about fairly small amounts of money relative to a large health expenditure bill for this country. We are talking about about $12 billion of additional health spending to cover all of the uninsured, because even that 25 billion in the Pepper bill is replacing to some extent individual out-of-pocket outlays for health care. So some of the uninsured are now getting care on a self-pay basis, so the government, even though it is spending 25 billion, that's not all new money in the health system. So there is really only about 12 billion, according to the Pepper Commission cost estimates, of new health spending.

Some of the plans that would have more comprehensive benefits, less cost sharing, might increase use

of services more and have a $35 billion impact on the health system. But we are still talking about less than 5 percent of total health spending in terms of incremental costs. It is the share of the pie of that spending that gets altered radically depending on which specific approach one is following.

COMMISSIONER ROGERS: Karen, in terms of -- and I'm glad you gave us those other figures so that they don't look quite so monstrous -- but I'd be interested in your feeling of if knowing that 70 percent plus percent of Americans say yes, this is an area in which I would be willing to spend more in terms of the health system, are you in any way persuaded by the Bob Blendon kinds of arguments that if you crafted some, as I say, from column A, some from column B, if you took some fro the private sector, some from the public sector you could get enough consensus to -- is there anything we could put together that could move, or is it the same experience we have had for the last 50 years in terms of universal entitlement? I'm wondering how far do we go here without sabotaging ourselves.

DR. DAVIS: I don't know how good my credibility is. Dr. Rogers funded me to write a book on national health

insurance that came out in 1975 --

COMMISSIONER ROGERS: It's a beautiful book. I recommend it.

DR. DAVIS: -- that talked about it being around the corner I think.

But, you know, Dr. Rogers is referring to the work of Robert Blendon at Harvard which has really looked at over 1,500 different public opinion polls conducted over the last 20 years. Actually, it was 1,500 the last two weeks. Anyway over some period of time.

And what the reading of that is, first of all he has found that people would be willing to pay more for health spending on the order of at least $100 a household, so there is some money that people are willing to pay for other people to get health care. But he has looked at the sources of revenue that people are most willing, or the taxes that people are most willing to have increased to provide say national health insurance. They are most supportive of tax increases that other people pay. So high on the list are actually taxes that employers pay, which workers do not perceive as being taxes that they would pay. So whether that is payroll taxes or premiums that employers would pay, those

are relatively more popular.

He said that there is overwhelming support for taxes on millionaires and increasing the upper bracket of the income tax so long as it doesn't get down into their bracket. There is a fair amount of support for targeted taxes on cigarettes, alcohol, those types of products. Then you get kind of further down into things like sale taxes, value added taxes. Personal income taxes tend to be at the bottom of things people are willing to have increased. So Dr. Blendon has argued that in fact you need invisible taxes to make it popular, whether those are employer paid taxes or taxes that are embedded in the products, sales taxes on certain products, et cetera.

So he would certainly argue for, you know, I think a variety of sources of funding. Again, if you are asking me my own judgment of what might be salable both to the broad American public but also to policy officials who are concerned about a large federal deficit, concerned about voting for anything, I think you are talking about something more along this Pepper Commission approach, something on the order of 24 billion, and maybe even that phased in in several steps rather than swallowing up that all at once.

And that in part looks low because it simply requires off budget that employers who are not now buying health insurance for their workers do so and that those show up really off budget or on the private account, so there are additional outlays on employers as well.

CHAIRMAN OSBORN: Phil Lee, and then Tim.

DR. LEE: I'm going to have to run, so let me just go to the broader questions.

Dave, to respond to your question about when, I guess you and I have been involved in this since at least 1961. Chairman Rostenkowski, at this recent retreat of the Ways and Means Committee -- and there were 30 of the 38 members present -- the whole retreat was on health care, and he said two things; he said we will solve the problem, and he said, second, it will require presidential leadership.

President Bush has instructed Secretary Sullivan to come up with recommendations to deal with these issues. The Under Secretary chairs a task force, so I think that that is a very important component of this process.

Karen and I have been recently involved with physician payment reform. It took three years of Commission work and then an additional nine months of action by the

Congress, so it was almost four years to simply reform physician payment in the Medicare program. So my guess is five years might be a not unreasonable time frame, but we are building towards that, and I think this Commission's particular role is to put AIDS and HIV within that broader context.

And I would suggest, one, as Karen has, that you are looking at the uninsured, and in fact also the underinsured, that you are looking at acute care and long-term care, that you are recommending comprehensive financing reforms. You are not recommending changing the delivery system or the doctor/patient relationship, but it is financing reform.

I would hope you would recommend universal coverage, portability of benefits, so that if an employee goes from one employer to another or if they are unemployed or they retire, they never lose their benefits. That there is a basic benefit package, and for those who wish more than that, they can then purchase that in the private market beyond what is provided.

There is both public and private sector responsibility, and it seems to me that one of the things

that you can do is to spell out as you see them those responsibilities. And I would suggest that the ultimate responsibility rests with the federal government to assure that every citizen of this country has access to a basic level of health care.

I would also include in a comprehensive financing reform cost containment as a parallel intimate part of the whole process. And finally, a significant element of health service is research built in, because you need to have an adaptable, flexible system. We are not going to answer the problems of 20/20 in 1990, and yet we are going to set in place the financing system that needs to adapt to those changes.

I would hope also that within the public sector -- and I think you have an opportunity to do this -- to define the role of the federal government, the state government and local government. You broadly define the public and private roles, but you say within the federal government here is the role for the federal government, here is what we think is the appropriate role for the state government, both in financing, in organization and delivery, and in regulation.

At least at the federal and state level there are

different regulatory responsibilities. Certainly the insurance regulation is an important role. At the state level there are some things that have been suggested there. That I think then creates a framework for all of the recommendations that Karen has suggested you consider as options or provide options for the consideration of the Congress as they move forward.

CHAIRMAN OSBORN: Thank you very much, Phil. That's a very --

DR. LEE: It was a pleasure to participate. Thank you.

CHAIRMAN OSBORN: Tim.

MR. WESTMORELAND: I had a question for Karen if I could. In the cost estimates down here, 24 to 225 and 12 to 35, do any of those include payment for prescription drugs?

DR. DAVIS: You know, that's a good point. The Pepper Commission proposal is a very limited benefits package that does not include prescription drugs. So most of these plans, in an effort to get the cost down, get the price tag down, stick with basically hospitals, physician services, usual expansion to prenatal delivery and infant care so you make sure you get immunizations, et cetera, covered.

Sometimes some limited mental health, but you nearly always stop short of covering prescription drugs. So no, those numbers don't include that.

MR. WESTMORELAND: That was my guess. And going back to the conversation that Harlon and I had across the room this morning, I don't think it is necessarily true that anything we do incrementally toward taking care of people with AIDS and HIV as incremental proposals will slow down or stop universal health coverage. I think they are proceeding on those parallel tracks. But I do think it's important for this Commission to recognize that a lot of things that are proceeding for universal health coverage don't do a whole lot of help for AIDS and HIV. I mean, it is the other way around, that the universal coverage plans don't address some of the things that AIDS and HIV would find most pressing, which in this case I think is ambulatory care prescription drugs.

CHAIRMAN OSBORN: I think if I could suggest that we could all stand to stand up and stretch and take a little break. This has been very rich discussion and I think again we can stand to absorb it a bit and then come back. Let's do take a break until 4:00, and then we'll come back and see

where we can go from the day's deliberations thus far.

Thank you.

[Brief recess.]

COMMISSIONER ROGERS: Could I get you all assembled again please.

Harlon, don't leave us. Let me capture all our Commissioners.

We are reaching the wind down, or perhaps the melt down point here. Let me make a few preliminary comments.

Karen, we are enormously grateful to you and your group, and I have heard comments from many of the Commissioners. This has been just an elegant session and we thank you for all the careful work. Just personally I would say in reading that document and seeing the amount of effort there, that's a wonderful piece of craftsmanship and we are much in your debt for that and we obviously are going to build very heavily on it.

Now let's see how far we can get in deciding what we will do in this particular sector, and we may not reach closure but let's get as close to it as we can.

From what I have heard this morning and just in the conversations in the hall, it seems to me we are all agreed

that we have got four or five rather general points in this financing area, and let me just try them out on you again to see if we are there, and then let's see how far we can go beyond that.

That one, this dreadful epidemic has made really glaringly evident the big gaps in the financing of health care that hurts this particular group. Second, that because many of them are poor, are from minority groups, they are disproportionately in that 34 or 38 million Americans that are underserved or underfinanced or not financed at all in terms of health care.

Three, that in the absence of being able to finance that care in some way, many of the recommendations of this Commission will fall short of their mark because we are unable to get those. They have to be woven in with primary kinds of services for these people. And let's see, four, that it will be enormously expensive in suffering, in loss of lives, and in economic costs if we continue to ignore that fact.

Ergo, the Commission -- and here is where I begin to disassemble a little bit -- but that the nation take aggressive, immediate, swift -- use your own adjectives --

steps to move us toward a system which will cover all Americans for basic primary care services; that as interim steps or as ones that we feel must be at a basic minimum, or as incremental steps -- again, use your own adjectives -- that we start with options which would move those with chronic relapsing kinds illness that we fail to deal with well right now into financing.

Six or seven, that the Commission has felt so strongly on this -- I'm making this up as I go along -- that we had asked Dr. Davis and her group to craft a series of options, which they have done. Eight -- and here is where I think we are if we can do it -- that the Commission feels it has enough competence to say strongly that we do A,B,C. I heard a number of ones identified that we could pick out that we could, or that we commend all of them to examination, or that we feel that some combination of public/private combines in taking some from Option 3, some from Option 5, some from Option 9, would best satisfy us because it would encompass or enfold the greatest number of people that are the primary concern of this Commission.

Now let's see how far we can get in terms of what this series of recommendations should -- let me add one other

thing, because Don, as you moved towards your microphone, Don pointed out the fact that Phil Lee as he was leaving gave us -- and Karen has said this too -- four or five sort of wonderful principles -- portability, comprehensiveness -- I wrote down a few of them and my list is now missing -- equity, cost containment -- that were the kinds of things that I think we want to put into those principles that we say are inviolate, that these we won't move from. I don't know how we craft this, but that these are critically important to the Commission, or what have you.

Now, how far can we get? Donald.

COMMISSIONER GOLDMAN: I just want to say that I think arrangements have been made to get that one statement transcribed and get it for tomorrow so all of us will have it.

COMMISSIONER ROGERS: Good.

COMMISSIONER GOLDMAN: I would just add that the one thing is when you talk about at least one of the points that you made, which I concur with, and you talk about the nation as a nation moving toward a system in which we have the kind of universal or national health insurance that we are talking about, I think that we ought to be a little more

directive as to who that is directed to and talk about the President and talk about what I think also Phil mentioned, that one of the things that was discussed at the retreat that he was referring to was that we were really not going to get anywhere in terms of resolving or developing a consensus about what kind of national health insurance program we are going to have until there is leadership as to development of that consensus from the President, and I concur and agree, and if the President sits around waiting for a consensus to develop around him before he moves and picks up his pinky about it, then we'll be all waiting a long time.

COMMISSIONER ROGERS: One of my instincts there, Don, is that that's part of who do we direct this toward. I mean, isn't that a more basic part? At the moment it is how far can we go in terms of recommendations for financing. It seems to me it is important to say who are we going to shoot at with all of our recommendations. That's item one on our discussion tomorrow morning for Commissioners. That might well precede what we do here.

But how far are you willing to go in terms of the financing issues?

COMMISSIONER GOLDMAN: The other thing I wanted to

mention is that -- we'll get into this tomorrow -- but one of the suggestions that I talked about was breaking up our report into different sections, and it seemed to me that an approach of this nature would be perfect in terms of doing what I was referring to in my memo in terms of some of the basic principles would be in the executive summary and then the details of the specific kinds of options and plans would then be in the supplemental or in a later-on document in terms of dealing with levels of complexity, which except in summary form really need not be in it.

So my suggestion would be to deal with them but to deal with them in that fashion, to talk about the principles and talk about the kinds of concepts in very summary form, but not to deal with the details of them in what I would consider our most important document in that process.

COMMISSIONER ROGERS: I'm trying to keep your feet to the fire in terms of what marching orders do we give Karen. And Diane, you had an important point earlier on here too that has to do with ownership of the document, who it is coming from and so on, which you may want to throw in here too, but say what you wish to say.

COMMISSIONER AHRENS: Thank you, David. Yes, I

will.

I have been taking notes on what you said, and I think you said it very well. When we are talking about the inner move toward addressing chronic population, I think that's very good to talk about chronic population needs. But in terms of AIDS to single out -- and I think what I heard as a consensus on the part of the Commissioner was that we have to hold up primary care, that all of the energies and resources are going into the acute care end, and we need to hold up primary care. And in connection with that, if what I heard was correct, that the early intervention costs 90 percent are drugs; that's where we bring in in terms of primary care the whole issue of the drug related concerns that we have.

I think it is important to get that into this sort of prologue or whatever we are talking about here.

And then I have a question. When are we as a Commission then going to deal with what we select out of the menu that is going to be a part of the presentation? And my understanding is we are going to take what Karen has provided us and say here is a panorama of the kinds of things that could be done. The Commission then we may recommend all of

them, we may recommend six of them, or a combination. When are we going to come to terms with that?

COMMISSIONER ROGERS: I guess one of my feelings is we come as much to terms with it as we can at this time in terms of marching orders; not closure, but saying here is as far as we can go, or we wish to go further, we wish to be more specific. We like ones from Option 3, from Option 5, from what you have heard over the course of the day and what you have read.

Eunice. Excuse me, Harlon and then Eunice.

COMMISSIONER DALTON: Okay. I would I guess start with Medicaid. I'm not sure overall how I feel about Medicaid. One thing though that I think we ought to stand for is that financing has to be provided for other than through employment. That is people who have never been employed or have been sufficiently underemployed so as not to qualify for job-based financing ought to be covered. So then in that sense it seems to me we want to do something about Medicaid or some other program that speaks to that population.

Whatever else we do about Medicaid, from what we have heard all over the country, it seems to me that not only

an AIDS diagnosis but HIV infection should be sufficient to trigger Medicaid. It seems to me that that's one of those specifics that we should consider and I'm suggesting that we should in fact put forward.

COMMISSIONER ROGERS: Eunice.

COMMISSIONER DIAZ: I would agree with you that probably speaking to the essence of what has been said today might be as far as we can go as to not tie ourselves too closely with anything that might come back to be haunt us in terms of looking at a more global proposal of services and the continuum of care. We have defined some of that in the document prepared by Scott's subgroup and in other work that the Commission has done, but I think that there are several overriding principles that we have heard today. And probably the only things that I would have liked to have questioned Phil Lee a little more about is one statement that he made, one I agree so much in terms of being able to give priority in whatever you write, Karen, to the underinsured and noninsured. I really think that is a very, very important point that he made.

However, I did disagree with something that he said that we have to prioritize in that package -- acute care.

Tim, you and I heard that, both of us heard it, and I would just wonder why he said that. Because I think the essence of what we have discussed today is really looking at the non-acute care, the ambulatory services, the integration of at that into primary care. So that would be one question I still have and when we see this transcribed tomorrow I would want to watch that very carefully.

DR. DAVIS: If I could interject there on Dr. Lee's behalf, I think what he said is that we need to look at both acute care and long-term care.

COMMISSIONER DIAZ: He did.

DR. DAVIS: And when he uses the word "acute," he means hospital services but also physician services, primary care, preventive care. So it is a somewhat different terminology than I'm hearing it used here when where people are saying "acute" they mean hospital, and I think what he was trying to say is that you need to think about the whole continuum, not just acute care, where he means by that primary care, inpatient care, but also he was urging you to think about the long-term care part of it as well.

COMMISSIONER DIAZ: I appreciate you clarifying that because it didn't make sense in terms of the rest of our

discussion.

COMMISSIONER ROGERS: I think part of what Eunice was hearing too was Tim's caution that don't let the enormous immediate needs of the very expensive hospital care deflect this totally from getting a primary system in place that in essence could care for those who are HIV positive but not enormously ill.

COMMISSIONER DIAZ: That's it, that's one point, and thank you for rewording it. But my last thought is that any examples you might be able to give of where this integration of HIV care might be more immediately seen, or the results of existing systems that with minor transformation or influx of dollars may have the capability of providing that continuum of care, primarily those migrant health centers, community health centers, already funded types of clinics there that model of care may be actually seen and implemented with some degree of success.

I think that it would be very important to tie in the financing recommendations to the organization and delivery of a system of care. Otherwise it is meaningless to the reader. They can see here are these options, and wonderful as they are -- I really like them all -- but it is

more like really a selection at a smorgasbord. Where are we going to pick? I mean, it is very difficult. We want to taste them all. They may have different applications by state, by region and by locality, and I think that if the report reflected that, I could think that what you have said in putting this in a tone that here is this smorgasbord and we have an opportunity now to select, but the applications of that selection will vary and depend, as Phil so adequately stated, federal, state and local responsibilities and our ways of looking at this epidemic and the impact of it.

COMMISSIONER ROGERS: Good. Harlon.

COMMISSIONER DALTON: Again with respect to Medicaid, I want to suggest that -- and I don't know how we would put this -- that extensions of coverage of Medicaid not be purchased at the expense of reimbursement rate or the quality of care purchased. In other words, I think we need to somehow figure out a way to say even more broadly that extensions of health care financing not be obtained by reducing the level of care that the financing purchases, and specifically with respect to Medicaid. One of the ways in which that might happen is by lowering reimbursement rates while including X number of other people. We have to oppose

that.

COMMISSIONER ROGERS: All right. Harvey.

DR. MAKADON: One of my concerns, I think a number of you have now talked about the need to really look at the non-acute or primary care system, and I think Tim has talked about, you know, early intervention, which clearly could be a part of that, or should be a part of that.

One of my concerns when we look at the options -- and I think they have been clearly laid out -- is that our current primary care system has been funded with those different options for different sorts of people. So that one of the reasons we do have a fragmented primary care system is in fact because Medicaid and Medicare payments are very fragmented and the end product is what we see.

So I think we need to look a little bit beyond the options in terms of financing mechanisms and look a little bit more carefully at what it is that will actually be financed and how that will be done. For example, the figure you gave about 90 percent of the cost of early intervention being for drug care, again, I wonder how much of that is -- I mean, a lot of it is true because drugs are exorbitantly expensive, but also to some extent it may be that the system

that has been looked at in terms of what the costs are has been modeled on a system that hasn't reimbursed very well for primary care services in the broadest possible sense, ranging from medical care to mental health care to home-based care, and I think all those things need to be looked at quite carefully.

So that I think it is easy to adopt a recommendation that we look at an incremental approach to providing coverage beginning with coverage for the poor and the uninsured, and I think that we could really demonstrate a great deal of support for that.

On the other hand, I also think we need to look at how that care is going to be paid for. And I think two thoughts came to mind in thinking about it here today. One is I'm actually sorry that Phil Lee left because I would be interested in hearing him talk some, and maybe Tim can a little bit, about the implementation of the relative value scale, which is being looked to as a Medicare payment system that would provide for better reimbursement for primary care services as opposed to other physician services. And yet from what I have heard from the group in Boston which has been working with the government in terms of implementing

that, in point of fact in terms of the process that's ongoing looking towards the implementation of that system next January, the added benefit for primary care physicians has been taken away and in fact it is going to look much more like a reduction in overall payments to physicians with perhaps relatively more going to primary care physicians and relatively less going to subspecialists and people who do procedures.

So again I think that's a potential model, the relative value scale system, which could be used to reward people who care for AIDS patients in a way that we don't currently do it, and yet I would be interested to see if that's feasible.

Another system which I think is worth looking at is how the reimbursement system in New York has worked, which has added reimbursement for people who care for a disproportionate share of Medicaid or uninsured people with AIDS throughout New York State. And my sense from a distance is that it has been an although sometimes cumbersome system, a good system for recruiting physicians. There are physicians who actually go and get jobs taking care of AIDS patients in New York, which certainly isn't true in Boston.

And it is worth looking at as a potential model as a kind of Medicaid option. And whether that is an optional option or a mandatory option, it is certainly something that we should know more about.

I think one final point, and this does go to hospital reimbursement issues that I think it is important to bring up, is that although we clearly do want to emphasize ambulatory care, and that's what I do and that's what I like doing and I want to be able to continue to do it, I think it is important for me that my hospital feels secure that when I admit patients to the hospital they are going to be paid for, or they would not look as kindly upon my doing primary care of people with AIDS in our outpatient department.

So that we need to be careful that we have to look at what the finances for the hospital are too, because the system does operate as a system and one of the problems that we often have is that we look at one piece or another. We are fortunate in Massachusetts that we do have an all-payer system so that if someone is uninsured or on Medicaid, the hospital really gets reimbursed reasonably well. If that weren't the case, I'm not sure that our institution would be as supportive of our ambulatory or primary care AIDS program

as it is.

COMMISSIONER ROGERS: Thank you, Harvey.

Charlie. Again, let's try and focus on what things do we want to come down with in terms of recommendations on financing.

COMMISSIONER KONIGSBERG: David, I guess I have a procedural question. Would it be well to start getting some of these principles down up on the board, because several of them have floated around, somebody with handwriting a lot better than mine so I'm automatically disqualified from writing anything; also that is tall enough to reach the top of the board. Because I think what we are doing, a number of principles have been enunciated here, but we are kind of rambling around, and would it be useful if we could just get them written down up there? Because I think that's the essence of what we need, and then it will be easier to start picking some options that we think particularly intrigue us.

COMMISSIONER ROGERS: All right, fine. Jane, are you volunteering?

I was trying to keep track. If you will permit me, I will indicate those that I think have already come out, which at least are part of it. Some of you have said a

primary care, ambulatory care emphasis without neglecting the inpatient end of it, but that we pay attention to that, that we have ignored this because of the awful crisis of the acute care needs.

I may have been too editorial on that. I heard drugs must be -- I'm going to use Phil's words -- accessible and affordable, and we don't like unseeming profits. That certainly was one of the things we have said and it is contained in some of those recommendations.

That we must cover other than through employers, because a lot of the people who are our charge are not employed.

Harlon, listen to this one, it is your piece here.

COMMISSIONER DALTON: I trust you.

COMMISSIONER ROGERS: We must cover other than through employers because a lot of our charges are not in there.

I heard that we have got multiple epidemics that may have different applications, Eunice, in different parts of the country.

COMMISSIONER DIAZ: Yes, absolutely.

COMMISSIONER ROGERS: And then I heard last from

Harvey that we might -- and I don't know quite where this fits but I agree -- we might look at the New York State experience with generous reimbursement in terms of what has that done. And I can report that it has done exactly what Harvey has said, it has made for much better care, it has recruited physicians, it has done a great deal to put a boost under the care of HIV positive people.

COMMISSIONER DALTON: I was actually trying to hear how much of what Harvey was saying was a recommendation and how much was a suggestion of stuff we might look at, but I think I heard you say that in trying to expand the current system in the interest of equity, fairness, that we ought to be cognizant of what the current system does and does not reimburse and that in whatever we do we should make sure that even the interim system that we come up with covers a range of services that's appropriate to the AIDS epidemic, even if it is more than our current system covers. Is that fair?

DR. MAKADON: Yes. I mean, I think my concern is -- I known my concern is -- that we have all talked about expanding primary care, and I believe that a good primary care system can take care of a lot of people with AIDS, even people with AIDS who also use drugs. Physicians need to be

appropriately trained and they need to be reimbursed for the time to spend with patients. That's something which isn't being done under many reimbursement systems in terms of reimbursement for primary care providers.

For example, our hospital subsidizes our primary care program out of its inpatient revenue in order to keep primary care physicians on-site. There is no way that our primary care practice could continue to exist if we didn't get subsidies from other subspecialties in the hospital. If we are really serious about emphasizing primary care, it should be able to stand on its own because that's the only way they are going to be able to reasonably recruit people and rely on revenue to do an adequate job. I was rather appalled when I was with --

COMMISSIONER ROGERS: Don't editorialize too far here.

DR. MAKADON: I was just going to say I was really quite surprised when I was with the director of an outpatient program from a major San Francisco hospital who said that his hospital really can never come to any agreement on a budget for a position for his outpatient program in spite of the fact that there is obviously a huge demand for care there.

And I think that that's unfortunate, but that's the way primary care funding is, and I think this group, since this is such an essential issue, should take a position on that.

COMMISSIONER ROGERS: Again, I'm going to feel that that is involved in the appropriate adequate financing of primary care so that it is not beg, borrowing and stealing and it also can encompass the treatment of drug use, et cetera. I mean, I think all of that is in our recommendation.

Charley.

COMMISSIONER KONIGSBERG: Okay. Let's see how we phrase this as a principle and see whether we get a consensus on it. We have got a health care system that is pluralistic. I would suggest that what we need is care that has multiple points of entry, both public and private, and, you know, this is picking up on the point I made, a concern I have had about not setting up a separate system of publicly financed care. But I think that could be rephrased and rather than in the negative just talk about multiple points of entry in public and private. I don't know about mainstreaming, that word I think is overused a little bit.

CHAIRMAN OSBORN: Please let's not do

mainstreaming, I don't like that one.

COMMISSIONER KONIGSBERG: Well, yes, but there is a principle in that too, June, in that we have got to get --

CHAIRMAN OSBORN: Yes, I just mean the word, Charley.

COMMISSIONER KONIGSBERG: But let's find another way. I have come to the conclusion I don't like that word either. It needs to be a part of the existing health care system, effectively done, if that's not some sort of oxymoron.

CHAIRMAN OSBORN: Well, the trouble with mainstreaming is that it sounds like the whole system is working well and that we want to be part of it, which is --

COMMISSIONER KONIGSBERG: That's right.

COMMISSIONER ROGERS: Tim, and then Scott.

MR. WESTMORELAND: I was going to suggest, and I think it is actually some of the thing Dr. Konigsberg is getting to, that one of the principles you might pursue is making sure that all current providers of primary care, be they community health centers of hospital outpatient clinics, contain some element of early intervention treatment. So that, for instance, the drug abuse treatment centers we were

talking about earlier provide some sort of early intervention treatment so that you don't have to send them to two different places. So community health centers, hospital outpatient clinics. And then, following on Harvey's point, make the reimbursement system reward that kind of behavior of complementary care, both the primary care, be it TB or drug abuse, and the HIV care.

COMMISSIONER KONIGSBERG: Exactly, and the care is part of every kind of, quote, practice. That's really the point.

COMMISSIONER ROGERS: Reward for single stop service.

MR. WESTMORELAND: And I actually would be reluctant to say it has to be single stop for everything, because we have a lot of primary care places right now that don't provide all kinds of comprehensive primary care. TB clinics and STD clinics come to mind. But I think it would be useful in those settings if we could provide early intervention HIV care as an entree.

Now, if I may go on there and say to the extent that you are looking for examples of that, the money is not out there yet but by the time you come to a recommendation

time, the categorical programs of Ryan White Title III, which is supposed to provide grants to community health centers and migrant health centers and places like that, and drug abuse treatment centers I think, should have some model like that if we can look to see how that's working.

COMMISSIONER ROGERS: Thank you. Scott.

COMMISSIONER ALLEN: This isn't along the line of the principles, unless you want to stay in that stream of thought.

COMMISSIONER ROGERS: No, I'm seeing how far would we like to go in terms of quite specific things.

COMMISSIONER ALLEN: Okay. I just have a question for Karen. You have laid out these options, but which would you recommend?

DR. DAVIS: Well, I think this articulation of the principles is very helpful for us, and so I'd like to say a few things about what I think the process is and then come back to your question.

As I understand -- and Maureen Byrnes can correct me if I'm wrong -- that what our task is at Hopkins is to now draft for you something we call a chapter of your final report, so it is something that goes out under your name, so

then you really have to worry about it. And having listened to what I have heard today, we will go back over our notes, but we'll try to reshape that document in terms of the principles and the criteria, some of the I think very eloquent way that David has expressed the problem with our current system.

And then I think the process is that first of all that's one chapter, and then are other chapters that people like Dr. Makadon and Dr. Coye and others are working on that have to do with delivery systems, have to do with state systems, et cetera. We will try to keep coordinated with those other chapter authors so that what you get is not just disjointed pieces but really an integrated document.

And then, again, as I understand it, our task is to come back before you in June at a meeting in Denver the first week of June. So at that point we expect to have this material digested, redrafted. So it is not your last chance to go through here. So that's what I see happening. This is an options paper to stimulate a discussion. We found out where people were. I think we have a lot of guidance now about how to go about drafting a final chapter that will come back before you at your June meeting.

But what I'm hearing out of this discussion and, you know, one always listens through these filters that make it not inconsistent with what one also truly believes -- if I could find my notes on this.

COMMISSIONER ROGERS: You know what you believe without even reading those notes.

DR. DAVIS: Yes. But we go through principles that you have articulated here, and the others we can find in our notes. Then I thought that the first statement would really be a recommendation on the part of the Commission that they would support comprehensive reform of the whole health financing system to achieve universal coverage in the population. So the question I have is then do you come down specifically at least to saying it ought to be a public/private system or it ought to be an all-public system.

If you ask me where I am on that issue, it is kind of the public/private. I would get universal coverage into a good system, a good set of benefits, high quality care, not sacrificing it by covering everybody by cutting down to an extent that we can't really provide good care. So that it is a question for you. If we don't get guidance, we'll probably draft that and go as far as we think you might go to actually

supporting a universal approach that would be a mixed public/private approach and you can tell us now or you can tell us in June, no, no, no, we don't want to go that far at all, or, in fact, we are comfortable saying what we would prefer in the long run but it's not that.

COMMISSIONER ROGERS: Diane, you have got a comment there. Let's interject it here.

COMMISSIONER AHRENS: Just a second on that. I'm a little uncomfortable going that far. I think it is a very political arena out there in terms of how this thing is conceived and how it is finally drafted, and there are all kinds of bills that say one thing and another. I'm not sure I want to go that far in saying this is what we think it should be.

I can't believe I'm saying this.

COMMISSIONER ROGERS: I'm with you. Go ahead.

COMMISSIONER AHRENS: But after all I said about the need for it, I just think that that's almost stepping out of our role and to just to say we have got to have this and there all kinds of possibilities but that's got to be hammered out. That's my feeling.

COMMISSIONER ROGERS: Diane, no, my goodness, I

think I have seen the coming of the Lord here.

But couldn't we -- it seems to me we can go fairly far down there, which is to say we want that, we want that coverage for these people. And you might be willing to go -- I agree, I don't think we could be doctrinaire. It would be quite unwise for us to say that we want to get to Chicago and we'll tell you exactly how you get to Chicago. I think we could say there are multiple roads to Chicago and in our judgment -- as far as we can go is that we think it ought to be some mix of public/private because it looks like that's what the nation might be willing to accept.

And there are a series of people who could give you -- or we have got a series of recommendations there, but that we are not willing to come to -- but as a basic principle we feel we must cover those people or it ain't going to work.

CHAIRMAN OSBORN: Could I make a suggestion here, that the one thing that I have heard even the most conservative of the people that we have talked to over the last 18 months move on is the issue of access, and access presupposes some kind of financing. And people who will not begin to be able to agree right now about how to finance have begun to all climb into the cart that says you have got to

have access, which I guess is David's getting to Chicago.

So I would think that we probably could make a very strong ringing statement about the need for access to care, that this needs to be -- that we don't -- our charge is HIV and AIDS, but that we recognize that we must do things that are prototypic and do them in a way that is entirely appropriate for a much larger group of people with chronic, relapsing disease, and that the specific mechanisms then are subject to some discussion and less precision. But that I think we could say with a great deal of assuredness, and it is close to what used to be a very arguable position. But my take is that it is no longer very arguable among people in leadership positions, even relatively strongly conservative in other ways, that that's where the movement has been even since this Commission started sitting, is on the overall issue of access.

So if we use that word as the catch word, then I think that we have circumvented some of the political flak that might otherwise quickly follow.

COMMISSIONER AHRENS: I just want to come back that maybe I was misunderstood or didn't say it clearly. No problem with that. My concern is whether we say yes, it

should be all public or it should be a combination of public/private. I guess I'm not willing to go that far at this time. That's what I guess I'm saying, that there are all kinds of ways of doing this, but we think it has got to be done.

COMMISSIONER ROGERS: Perhaps we could push the penny a little bit farther, Diane, in terms of saying we know that Americans are now quite willing -- say they would like to spend more here, but the rock on which we floundered each time we have moved this direction has been that people have been quite doctrinaire, that they have said it should be all private, that it should be all public, and it looks from the evidence we have before us that it should be some -- that some combination of this might work.

Well, I'm running out of gas here, but there is a fair amount of evidence in there that we could say Americans wish this but that we do not wish to be too doctrinaire but we must accomplish this, that we must accomplish this.

DR. DAVIS: Certainly in terms of public opinion polls, they do break on that issue of whether it should be largely a mix of employer based and public programs to cover everyone else, or a single government-run plan.

COMMISSIONER ROGERS: We could say that, but saying we feel must accomplish this.

COMMISSIONER DIAZ: Kind of a combination of what June was saying and you just finished saying. If we couch that in a language that would reflect the reason for this, the Commission after examining the various methods of financing of the care of the poor population, looking at the gaps and needs that currently exist, a system which offers greater accessibility, da, da, da, will meet -- you see, it is the same thing, but focused on creating greater access for a majority of the population that is uninsured or noninsured da, da, da.

COMMISSIONER ROGERS: That have been left out.

COMMISSIONER DIAZ: Yes, that have been left out of the system.

COMMISSIONER ROGERS: Harvey.

DR. MAKADON: I wonder whether a good way of kind of describing the problem and some of the solutions in a way that people can reasonably well understand them would be to use vignettes from people who have testified before the Commission in terms of who are these people who aren't insured, what their problems are, so that we could look at

different types of people in real terms instead of let's say a pie chart that looks at percentage of people uninsured.

And concomitantly, I think looking at the options as an incremental graph that might look at, you know, these are people living with this kind of income, these are the potential options for this group, and trying to give people something to compare with a sense of who it is that we are talking about in each of those little boxes that would get filled in. It might be an easier way for everybody to conceptualize this than eight options which have some degree of overlap and some degree of separateness.

But again, I think tying a real story to the different parts of the graph and to the people who are uninsured might be a good way to portray this.

COMMISSIONER ROGERS: Yes, I view that as how do we market this, how do we put punch to it, how do we get the human element into that.

Charley, Scott, Don.

COMMISSIONER KONIGSBERG: Well, I would support June's comment, that I think it is becoming more and more, quote, socially acceptable to critically examine the health care system. In my own state there was a bill introduced in

our legislature this year that was a universal access all-payer system. I don't know where they got it from, but it will be referred to an interim study. We had organized medicine, organized hospitals, together with AARP, nursing home groups, all coming forward and saying we are not sure about the doctrinaire parts of that bill, but we are sure that it's the kind of thing we need to discuss.

There was virtually no opposition to at least discussing it. That's a radical change, and it comes later to Kansas than other places, but not after considerable careful thought. So I guess I would support taking a pretty strong stand about the universal, the access issue, but not getting too doctrinaire, because I think we will get chopped down, but stick to those principles.

COMMISSIONER ROGERS: Good. Scott.

COMMISSIONER ALLEN: Just a word. I feel more comfortable with access, but I think we ought to heed Tim's warnings about HIV not being included at all, that it may be detrimental if we are just advocating for a national health care system, but to say do not forget those with HIV and do not start this discussion or continue this discussion without the inclusion thereof.

But back to the original question to Karen, you mentioned one. What else do you recommend? I would like to know because it is going to be very important.

DR. DAVIS: You know, of the specific options that we set forward for you today to think about, you know, after saying kind of where we think we ought to go in the long term, if it were up to say what some incremental steps were and getting awfully specific, I think a subset of those -- first of all, the one that Tim Westmoreland mentioned, instead of the Medicaid two options that we have in there now where you are talking about -- first of all, I didn't think there was much support for the second one, we are not very enthusiastic about the second one. But that first one on expanding Medicaid to cover everyone with HIV and AIDS who is below the federal poverty level, I think what Tim said, well what about an option that for those states that wanted to do that then there would be federal matching monies to do that. I think that at least going that far is worthy of consideration. Then those states -- California, New York, whoever they may be -- that are willing to take advantage of that at least have that available.

And right now you can be desperately poor, you can

be HIV positive, but there is no way, unless you meet disabled criteria or a pregnant woman with children or an AFDC criteria, that you can get coverage. So to me that doesn't seem too far out on a limb, to say at least give states the option, and again the precedent in this history are the Medicaid expansions, which the governors may now be aware of, that when you make it an option next year it may be a mandated benefit. But at least this Commission was saying let states have the option of going ahead and covering these people at the point they are HIV positive instead of waiting until they have full blown AIDS, because it is consistent with the principle of wanting preventive primary care and a good system of care that doesn't wait until people are so seriously ill and in a hospital to really trigger any financial support. So that's one.

The second one, truthfully, out of all of those if you ask what is near and dear to my heart in terms of interim measures, it has to do with the Medicare options. Certainly permitting people to buy in is viewed as again a more modest proposal than simply eliminating the waiting period, or if you were doing the waiting period, shortening it by six months rather than the whole two years is a more modest step.

So something in that Medicare line strikes me as making it -- it would be a very attractive -- again, I don't know, you will have to think how far you want to go. If it were up to me, I'd support Option 3. If you want to soften it a bit, you could say it deserves serious consideration or whatever and lay out the analysis. So there are different ways you could posture yourself as a Commission without kind of a bold headline saying, "They have recommended a $2.5 billion program that's going to..."

And I think certainly all of these incremental options to put them in the context of strengthening current programs to meet the needs of the chronically ill.

COMMISSIONER DALTON: Excuse me, you said Option 3; do you mean Option 4 with respect to Medicare?

DR. DAVIS: Actually I was talking three, that one that is more the voluntary. If it were up to me, of course, I would just eliminate the two-year waiting period. But it is very expensive. It runs into this whole do you put money into kids or do you put money into adults, et cetera.

COMMISSIONER ROGERS: Karen, I sense one way we could get at this that the Commission might buy would be to say in essence, our fond hope would be this, but that -- and

that the following options go incrementally toward this, that Option 2, or whatever it is, moves us part way, Option 3 would move us yet further. In essence, we could say that the Commission is -- here is the ideal, short of the ideal here are steps that might be taken that would push the peanut down that particular road.

DR. DAVIS: Right. So you have almost got a short, intermediate and long term, and the long term is universal coverage; in the short term it is optional coverage for HIV, people under Medicaid, it is letting them buy into Medicare. The intermediate term might be automatic coverage of everybody who is poor with HIV or AIDS, or letting everybody buy, or automatically be covered under Medicare.

The other two points that I guess of the options that we put forward, you know, I need to regroup with my colleagues about the drugs. But the thing I wrote down in the margin was work with Tim Westmoreland to come up with what makes sense on this. And certainly it seems to me that trying again with fixing the glitch in the Orphan Drug Act so that you can use that 200,000 threshold for drugs after they are marketed and not just apply that at the beginning seemed to make sense, and there may be some other little things in

there that weren't in those amendments that could also be surfaced.

Then finally, the Ryan White, I'm still trying to learn a little bit about how it is working in practice, and I guess maybe the point is it is not quite working yet in practice.

COMMISSIONER ROGERS: No, it's not.

DR. DAVIS: But it seems to me that's a vehicle that is out there and that certainly some modest expansion perhaps of funding for the prevention and primary care using the Ryan White authority would be something that this Commission could go on record as being supportive of as an important initial short-term step.

COMMISSIONER ROGERS: Again, that's another example it seems to me. I mean, I think this Commission would say, as we have, that we would wholeheartedly endorse and encourage and strongly support the full funding of Ryan White, that this was a lousy way to go to with great fanfare pass it and then starve it to death. That's editorial.

Short of that, here are the things that could be recommended to make it better fulfill its destiny.

COMMISSIONER GOLDMAN: One of the things we didn't

mention in the principles, although we discussed it earlier, is just the importance of dealing with issues involving AIDS and HIV infection in some other broader context, and I don't know whether or not you want to really include it. I think it is appropriately included as a principle, but I just want to discuss it with you. As Karen said in her report, that, for example, the idea of simply mandating coverage for all those who are HIV positive, it is unlikely to be politically or socially acceptable to extend coverage to an AIDS and HIV infected specific population and not to all low-income individuals with similarly serious diagnoses such as cancer. And I think that's a correct observation, and I think that's a principle that we ought to deal with.

And on the other side of that coin, and again, one of the things that I would love to see is some of these recommendations perhaps modified or changed in accordance with some of our discussions. On the other hand, it seems to me that we can get into and start getting a larger chunk by discussing perhaps some changes of definition of disability, which would generate more being people being qualified in terms of what the appropriate definition of disability of someone with HIV infection is, and maybe it ought not be

having to have PCP, maybe it is enough to have a T4 count under 200 and then that's enough, or some other kind of definition which would in a more gradual way bring people in without violating that principle.

COMMISSIONER ROGERS: I think that's a very good point. I think that is not part of the financing session but is an important part of what our report should contain.

Karen, we have given you some -- do you sense where this Commission is in terms of --

DR. DAVIS: Right. If you cut it off before they react violently to anything I propose, then I'll read into that concurrence.

COMMISSIONER ROGERS: Well, but it seems to me I have been hearing that we support this ideal, here are steps that might move us toward that. They are incremental. It is that kind of general thesis that we are shooting at.

COMMISSIONER ALLEN: You didn't mention the private health insurance option?

DR. DAVIS: I didn't deliberately. You know, I kind of skimmed through all nine and which of the ones I would feel most strongly about, and somehow I would stay away in this report from the small group market reform. Again, it

reflects my own biases. I think that is a little bit of a red herring. I think a lot of energy is going into it, I don't think it is going to solve the problem of small business anyway, aside from this issue of HIV/AIDS, and I certainly don't think it is going to solve this problem specifically.

Because, I tell you the way to get around it. You can regulate private insurance and say "Thou shalt not, thou shalt not, thou shalt not," but then you got to marketing practices, and is that salesman going to show up at the beauty shop and try to get them to sign up with their company? And so it is one thing to say you have got to take everybody, but they are not going to really outreach. They are going to try to make people dissatisfied, you know, delay paying the bills. So when you are trying to regulate them into doing something they really and truly don't want to do, you may think you have solved the problem but it is just going to be hidden away and fought in other ways. So I think it misleads people, all of those ideas about small market reform, to think it is going to solve a problem when it is just going to put off really a problem.

COMMISSIONER GOLDMAN: That's why I suggested

allowing them to buy into the FEHB, which doesn't mandate that and which turns over the administration outside of it and provides it as an option on the part of the employer.

COMMISSIONER ROGERS: I want to be sure all the Commissioners have at least had some input. This is not the end, but we want to give Karen as clear a shot at recrafting as we can. Larry.

COMMISSIONER KESSLER: I guess I'm a little nervous about the definition of disability and how that is beginning to get played out now with the private insurers and with Social Security, who are beginning to ask, I think quite correctly, just how disabling is HIV disease now that we, you know have long-term survivors and so on and more people in the workplace, blah, blah, blah.

There is a cut line when you talk about those who have access to care, primary care, and the poor versus the middle class and the uninsured versus the insured. But before we talk too much about AIDS as a disability, we might want to do a little market research about what is going on in terms of a shift. I think it is coming, I'm not sure, but maybe Harvey or Tim have other insights there. But it seems to me we have heard, at least in Boston, in response to a

number of news stories and so on that insurers are trying to cut people off disability, and that even SSI is getting very nervous vis-a-vis the six month review process.

That I think could be a factor when we describe putting all people with HIV on Medicaid.

DR. DAVIS: Just to respond to that, certainly the trend with pregnant women and children was to cut the link with welfare so you don't have to qualify for AFDC to get Medicaid. And kind of what we have been doing today is assuming you would get cash assistance from SSI and then get Medicaid as a result of being an SSI person, or assume you would get cash assistance as SSDI and therefore have the right to buy Medicare. And it may be that they are not so disabled they can't work and they may actually not need in all cases the cash assistance, what they need is the insurance that currently the only route into it is through SSI or SSDI, and maybe what we ought to be thinking is a little more broadly about breaking the link and not conditioning either Medicaid or Medicare on qualifying first for those cash assistance programs. And so I think it is a good point that you are making.

COMMISSIONER ROGERS: We are going to wrap this up

in five minutes. Tim, I'm going to call on you, and then Jim, but I want to be sure Commissioners have had their input too.

Tim.

MR. WESTMORELAND: Just very quickly, I think that's exactly the point, you don't need to get to the disability standards if you go ahead and provide health insurance on the basis of something else. The only reason disability is important in the financing discussion is as a route to the insurance of Medicaid and Medicare.

COMMISSIONER ROGERS: Very good. Jim.

MR. JIM ALLEN: I certainly support that, and I think that Larry raised a very good concern, but I think it can be dealt with if it is handled adequately. And while people are doing that, I think it is important also to take a very careful look at the medical definitions that go into the diagnosis of AIDS from a clinical perspective and break the link with the surveillance definition so that CDC doesn't constantly get jerked. We need to deal with this as a medical problem input of surveillance.

COMMISSIONER ROGERS: Yes. Very good, thank you.

Scott.

COMMISSIONER ALLEN: Just one quickie. You said if someone didn't scream you may go on from here. I feel that you are probably correct about the private health insurance and the regulation of the private health insurance, but I would like to see in the piece something that deals with the private accountability and that these are -- I agree with all the suggestions that you have here, whether they are practical or not I am not sure in the final analysis -- but I think there needs to be something articulated within the piece concerning the private insurance and their accountability to this epidemic. Thank you.

COMMISSIONER ROGERS: Don, any comments?

COMMISSIONER DES JARLAIS: A comment on private insurance. You know, if you start with the idea that private a insurance company is in the business because they want to make money, then the only way they will aggressively market insurance to people with HIV or at risk for HIV is that you somehow build in payments that they are actually going to make a profit on it, which means that those premiums would have to be awfully, awfully high. So I really just don't see how we are going to regulate those people to go out and seek a market unless they feel they are going to make money on it.

And I think then if they do make money on it, then we are really pricing ourselves out of providing the services.

COMMISSIONER ALLEN: It is not the recommendation, it is more of bringing to light the practices and how it puts the rest of us in this mess.

DR. DAVIS: And it also is a rationale for why you need to do something like Medicare expansion or Medicaid expansion, that this problem is not being met and that the insistence is that it be borne as a social responsibility and social cost.

COMMISSIONER ROGERS: Karen, we thank you. It has really been a wonderful day. I have found it very productive. You have given us a lot to chew on. I think we have given you a series of at least broad and semi-confused kinds of suggestions that I hope you can incorporate. This will not be the last time we see this.

A thought which occurred to me here as we were closing, which is, obviously, we are all going to be continuing to think about this a bit. If there are specific suggestions that any one of you as individuals wishes to add, let's communicate those to Karen. I think as you go home on the plane or whatever you my think, I'd like to give her a

little bit more direction on this one.

Karen, I'm sure you would welcome that as you continue with your labors.

DR. DAVIS: Certainly.

COMMISSIONER ROGERS: I'll turn it over to June to close the session.

CHAIRMAN OSBORN: Before I do, I just wanted to comment to Karen a personal note of thanks. As she knows, I'm dean of a school of public health and therefore I'm supposed to understand a lot of things, many of which I don't, and you just moved me along a lot today, so I'm personally very grateful for some importantly clear education on areas that are not my forte. I think a number of us -- actually, a number of people commented that to me in conversation at the breaks too, so an exceptionally helpful job of bringing us along to understand the issues that we need to grapple with. Thank you.

COMMISSIONER ROGERS: Maureen reminds me, let me give you your marching orders for tomorrow. We will meet -- and this is primarily for Commissioners to talk to each other in terms of what sort of three or four basic ground rules about our final report. We will meet here. We will pull

that table in so that we -- we do not have that small a room but we will try and make this a smaller circle so that the conversation is easier, and we will spend two hours rather singlemindedly on those four queries which I put before you, which I think we need to settle as a group, and then I hope if we have got a little time we will also outline what are our plans for our subsequent meetings coming to that final report.

CHAIRMAN OSBORN: And David, one thing I would comment additionally, that while we keep referring to it as a final report, everyone should know that it is -- Maureen has got a good term -- comprehensive report, because we have been extended and we will be continuing into the third year, and so that it is not a definitive last word kind of thing. And I think that's important in terms of everybody's thinking too. We don't have to have every "T" crossed and "i" dotted by the end of August or we don't get anymore say. Now, in addition to the OMB budget and whatever, I gather there is a letter more or less on its way from the President telling us that we are good people.

[Whereupon, at 5:10 p.m., the meeting was adjourned to reconvene the following morning at 8:00 a.m.]