# TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYDROME

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Pages 1 thru 262

Washington, D. C.
March 15, 1990

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NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Thursday, March 15, 1990

8:40 a.m.

Pan American Health Organization

Meeting Room B

525 23rd Street, N.W.

Washington, D.C.

COMMISSIONERS PRESENT:

June E. Osborn, Chairman

David E. Rogers, Vice Chairman

Diane Ahrens

Scott Allen

Harlon Dalton

Eunice Diaz

Donald S. Goldman

Don C. DesJarlais

Larry Kessler

Charles Konigsberg

Belinda Mason

J. Roy Rowland

Edward D. Martin (Representing Richard Cheney)

James D. Mason (Representing Louis Sullivan)

Jim Allen (Representing Louis Sullivan)

STAFF PRESENT:

Maureen Byrnes, Executive Director

Carlton Lee, Chief Liaison Officer

Thomas Brandt, Director of Communications

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PROCEEDINGS

CHAIRMAN OSBORN: I want to welcome you all to the March meeting of the National Commission on AIDS. In particular I want to welcome Jim Mason again, who tells me that Secretary Sullivan will be with us at some point during the day, but we are awfully glad that you can be with us, Jim. And Vice Admiral Ed Martin, for Secretary Cheney, is former Chief of Staff, Deputy Secretary of Defense for Professional Affairs and Quality Assurance. We are very glad that you can be with us.

I really don't need to introduce Congressman Waxman to this group, although I do want to thank him for the many roles he has played in the extraordinarily broad number of issues that have come up in the AIDS epidemic over the years. Most recently, I believe, he gave an important additional push to the Americans With Disabilities Act, which was ultimately reported out 40-to-3, and I think Congressman Waxman had quite a lot to do with that and some of his wonderful remarks.

Joining him is Judith Feder, Executive Director of the Pepper Commission. Today, we are going to ask Henry and Judith to wear Pepper Commission hats and talk to us, since

we have sometimes commented that there are so many issues in common that we should be very well aware of each other's interests.

Thank you very much for joining us.

STATEMENT OF HON. HENRY A. WAXMAN, REPRESENTATIVE IN CONGRESS, STATE OF CALIFORNIA, ACCOMPANIED BY JUDITH FEDER, EXECUTIVE DIRECTOR, THE PEPPER COMMISSION

MR. WAXMAN: Thank you very much, Madam Chair and members of this Commission.

I guess I appear before you in a number of different capacities. First of all, I appeared before you as a sponsor with my colleague Roy Rowland in creating this Commission, and I am pleased to get all the reports that I have received about the hard work that you are all undertaking in trying to deal with all the difficult issues that relate to AIDS.

Secondly, I am appearing before this Commission representing another commission, the Pepper Commission, to give you some bit of a report about what our recommendations are in terms of access to care for all Americans.

Thirdly, I come before you with some apprehension, because I look around the room and recognize the fact that almost all of you have testified before me, and now you have an opportunity to reverse the tables. So please, have mercy upon me.

I want to touch on the Pepper Commission because I

think the debate on the access question is going to be channelled quite a bit by the recommendations of this Commission. The Commission was very diligent in its endeavors. It was chaired by Senator Jay Rockefeller, who did an incredible job of keeping us on track, pushing the issues, making us recognize there were no easy solutions but yet struggling to try to find a common ground.

We came up with recommendations in two areas in which we had a charge. One was in the area of access to care, and that's what I want to particularly talk about. The other was in the matter of long-term care for the elderly and disabled, which is not an insignificant issue for AIDS patients, we hope at some point down the road, but right now it is not the major concern for most of the AIDS patients.

The access question has bedeviled us all when we recognize the fact that there are 31-37 million Americans with no insurance. They are not old enough or disabled therefore to be eligible for Medicare; they are not poor enough for Medicaid, and the reality is that 28 million or thereabouts of this group are working people. They are working people at jobs that do not afford them the opportunity for health insurance, which is the way most of us in this

country get our health insurance.

If we were starting from scratch to design a system where everybody in America would have access to care, I don't think we would have chosen the route of building on the existing health insurance system through employment. But the Commission decided that it was more realistic and practical and doable to build on the existing system rather than to start all over again.

The major thrust, therefore, of the Commission's recommendation was to make sure that working people would have coverage by mandating for large employers that they make available to their employees health insurance options and encouraging smaller employers, through tax credits and other incentives, to provide insurance options for their employees.

For those who would not be covered through the workplace, a new public plan would be created to replace Medicaid. The idea of the public plan was that it would not just be for the poor the way Medicaid is now. It would cover the poor, but it would also cover those people who would otherwise fall through the cracks, those people who have periodic employment, those people who are not full-time or even part-time employees as we might define it in the

legislation, those people who are not just at the poverty line but above it, who would not have insurance through any other means. Those people would be part of the public plan.

There would be a subsidy for those who were above the poverty line, and full compensation for the insurance coverage for those below the poverty line.

The notion was that if we are going to end the two- or three-tiered health care system in this country, a public plan could buy a private insurance policy for those who would be in that public plan, and an employer might well choose to buy his or her employees into the public plan as an option as opposed to a private insurance plan.

Now, this of course has an impact on people with AIDS, because people with AIDS are first of all concerned about access to care. It is obvious these are the most troubling of problems for people with AIDS, and very much part of the Pepper Commission recommendations, not only do we provide a way to get coverage through employment but we require that there be reforms to the insurance regulatory system that would eliminate pre-existing condition exclusions, no denial of coverage for any individual in a group, and a community rating--not individual rating--of insurability,

with the same terms to all groups in the area.

This, of course, would mean in effect that we would be spreading the risk for the cost of care for those patients who would have AIDS or HIV infection throughout the whole population. One of the advantages is obviously slowing down the push for the cost of care for people with AIDS from the private to the public sector.

The marketplace now drives AIDS testing policy, confidentiality, and employment discrimination. Employers are obviously worried about having to pay for health insurance coverage for their employees who may be infected, and not only that, the fear of lack of access to care can keep many people who are potentially infected or in fact infected from going in for testing and counseling, which could mean that they would have early intervention care.

The recommendations also would do away with this Catch-22, and we have this Catch-22 now in the Medicaid law, and I am going to get to that point specifically, but there is a Catch-22--if we cover people for health care services under Medicaid, we cover them because they are poor but also because they are disabled. We now have the ability to keep people from getting disabled by drugs that can prevent

pneumonia, prevent full-blown AIDS, or at least stall it off for some period of time. But they are not eligible for the early intervention drugs under the Medicaid program, because Medicaid is tied to eligibility based on disability. This Catch-22 under the Pepper Commission recommendations would not be a problem any longer.

Finally, these insurance reforms would make it possible for working Americans with AIDS and HIV to get and keep private health insurance. We have these redlining practices. It offers many middle-class people the option we have offered to poor women with children over the years: They could either work without health insurance, or leave their jobs in order to become poor enough to get welfare with Medicaid. It is an incredible dilemma to put people in; it makes no sense. The community rating and elimination of the pre-existing condition restrictions will make the private health insurance market accessible for people with HIV.

Having said all that, let me quickly say that implementation of this Pepper Commission recommendation is a long legislative way away. It will not be enacted tomorrow. There is going to be some period of time before enactment. But even if it were enacted immediately, it is going to be

phased in over seven years. So in terms of this epidemic, those seven years can seem for ever. And even if it were phased in tomorrow, it is not an ideal package, because one of the limitations in the basic insurance package is that there would not be prescription drug benefit included which is, of course, a serious omission for people with AIDS.

Well, while we work on the long-term reform of the system, we have to deal with some of the immediate problems in access to care for people with AIDS. We have immediate AIDS health care financing initiatives that we are going to be pursuing in Congress.

We are working on two packages of legislation. One would be improvements in Medicaid for people with HIV, and the second would be grant programs to provide early intervention care throughout the Nation and emergency assistance for high-incidence cities.

First of all, the Medicaid package. We are looking at four provisions in the Medicaid area. Expansion of the eligibility category, I alluded to earlier. Rather than force people to be disabled because of AIDS, we would allow eligibility by virtue of the HIV infection in order to get the early intervention drugs. It is an obvious elimination

of this crazy Catch-22 for Medicaid patients. I mean, we could prevent sickness, but the only people we are willing to help are those who are already sick. Rather than keep people productive, we let them deteriorate. So it is stupid, it is expensive. You should understand that for budget purposes, the CBO and the Bush Administration are very reluctant to assume that coverage of early intervention is affordable. They look at the cost of the drugs AZT and Pentamidine; they don't look at the cost savings from those who would not be hospitalized as a result of this early intervention.

The second legislative initiative is increased payments to hospitals with high-volume AIDS cases. These hospitals do not have the ability to shift the inadequacy of the Medicaid reimbursement for AIDS treatment onto their private pay patients--they don't have private pay patients. These hospitals are under an enormous financial burden, and I know this Commission recognizes that fact by virtue of the realization you have gone to a number of these hospitals and seen the conditions there.

Those hospitals, it seems to me, cannot stay open if the burden is going to be increased, and we know that burden is going to be increased. So under the Medicaid

provisions, we would require a higher reimbursement level to those hospitals that are treating 50 percent of the AIDS patients in the United States.

There is a third Medicaid piece. In the COBRA law, we provided that there would be a transition period after people lose their jobs, and they could have private insurance; but people who lose their jobs and who have AIDS may not be able to continue to pay for that extension of their private insurance. We would allow the States the option at their choices to pay for the private insurance coverage for that two-year period, which would be the transition before they would be eligible, if they live long enough, for Medicare coverage under the disability provisions. So we would give the States the option to pay for the COBRA continuation.

And then the last Medicaid piece would be a community care provision for children. We would allow the States to provide noninstitutional care wherever possible.

We also have, as I mentioned, two grant programs. In addition to the programs for the very poor, which are the Medicaid programs, we would try to do more in the area of prevention--and prevention in two ways--preventing AIDS from developing for those who are infected, through early interven-

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tion drugs, and prevention of the infection itself.

The program would involve a grant to States and clinics for counseling, testing, diagnostics, and early intervention drugs. People are not going to come in to be tested and counseled if they don't feel that there is a chance for anything that can be done for them, and if they can't afford to pay for those early intervention drugs, the incentive is enormous for people to know their HIV status. If we will make available to them those early intervention drugs, that can prevent the infection from developing into the disease. It also can prevent the infection of other people through the counseling of those who come in to be tested.

And then our second grant program is an emergency assistance program to those hardest-hit cities. We have a number of cities that are struggling with the burden of the AIDS epidemic far more than anywhere else. I know this Commission has supported these efforts. Clearly, we have to assist local governments and voluntary agencies that have provided care for so long.

Let me conclude by saying that many people have decided this epidemic is over, and the worst has already

passed; the reality is not that at all, and in fact, the worst is yet to come, especially when we recognize that all those who are infected--and there may be a million infected people in this country--are likely to need health care services as that infection takes its course if there is no early intervention to keep it from taking its ghastly course into a full-blown disease and all the illness that will require care before the inevitable death will result.

I thank you for allowing me to come before you. I'd be pleased to answer any questions, and I just want you to know how much all of us in the Congress are looking to you for thoughtful recommendations that can guide us in dealing with the many problems that we know of now and that are yet to come as we struggle with this epidemic.

CHAIRMAN OSBORN: Thank you very much.

Ms. Feder, do you have comments that you would like to make before we get to the Commission's questions?

MS. FEDER: I think that Congressman Waxman has always covered the issues well, and I just would like to say that not only am I available today for any questions you might have, but that the Pepper Commission staff would be delighted to help you. We are all in an effort together, and

we would be delighted to be of whatever help we can be.

CHAIRMAN OSBORN: Thank you so much.

I know that your time is limited, Congressman, but if you have time for a few questions--

MR. WAXMAN: Surely.

CHAIRMAN OSBORN: Are there questions from the Commissioners?

Yes, Harlon Dalton, and then Roy Rowland.

COMMISSIONER DALTON: First of all, I want to say that I'm truly impressed and a little bit humbled by the creativity reflected in the Pepper Commission's report. I wish we'd do nearly so well. Building on the current system obviously required much more ingenuity than starting from ground zero, and it is really a quite impressive document.

My question, though, is not about that report but about the improvements in Medicaid that are being proposed. You indicated, quite sensibly, that getting the Pepper Commission's recommendations implemented will take a while. What about the Medicaid improvements that you talked about--how soon can we expect those?

MR. WAXMAN: We have made a presentation to the Budget Committee, asking them to put aside funds in next

year's budget so that we could get started with these Medicaid initiatives. The CBO estimates are high, higher than I think are realistic, and we are going to continue to negotiate with CBO and try to get them to look at the savings side of the equation, not just the cost side. It will be a struggle, but we will be stopped in our tracks unless the budget will provide additional Medicaid funding. We hope to get this additional Medicaid funding so that we can get started with these Medicaid initiatives. I think the need is clearly there. The States are pressing for it because without these initiatives, they know that Medicaid costs are going to be much higher because cases were not dealt with early and because they won't have some of these options available to them to more rationally deal with the costs for care.

So we are looking for that hopefully in the short term.

CHAIRMAN OSBORN: Dr. Rowland?

COMMISSIONER ROWLAND: Thank you, Madam Chairlady.

I just want to welcome my colleague, Henry Waxman, here, and acknowledge publicly that he was in large part responsible for the creation of this Commission because after

it came out of the House Veterans' Affairs Committee and was considered in the Energy and Commerce Committee, it moved in an unbelievably rapid period of time. In two days it moved from his subcommittee to the full committee to the floor and became a reality, and that is just almost unheard of, and it was largely due to the efforts of Congressman Waxman that that happened.

And you can see what you have to create is a working commission. Every Commissioner is here, and that is most unusual for any commission, and you would find this to be true in almost every meeting and every site visit that we have had so far, that almost every Commissioner is there and working and I feel really good about that.

As you said yesterday, we met and talked about some of the things that need to be done, and you pointed out the Catch-22 situation that we have with reference to Medicaid, where an individual who is so positive is not eligible for the drugs that will help to delay the onset of the disease itself--certainly a situation that will be addressed, I am comfortable to say.

Also, we talked yesterday about the urban versus rural areas, too, and I think that is a Catch-22 situation.

While we have 13 cities in this country that are devastated by AIDS, we haven't gotten to that point in the rural areas, but we are getting to that point.

So I say that we have a similar situation in the rural areas and that we need to move to do something to address the increasing problem in the rural areas, where the greatest percentage increase is taking place and not overlook that as kind of a Catch-22 situation also. We discussed that yesterday, and the Commissioners are well aware of that, and we will be visiting a rural area in our country next month to look at that very problem.

So I just wanted to make those comments. Not only did I not have any hard questions--I don't have any questions at all. So I will just thank you.

MR. WAXMAN: Well, let me respond, because even though you don't have any questions, I want to make a very quick comment. First of all, the speed in which the legislation starting with the Commission moved was more a tribute to everybody's confidence in Dr. Rowland's recommendation that such a Commission could play a very useful role, and we are all very pleased that he made the suggestion and that this Commission is a reality. I am impressed to see a Commission

where every member is in attendance. Dr. Rowland knows, since he and I are usually always at our committee meetings, that we don't have a committee where very member is able to attend or willing to attend every meeting.

I think you are absolutely right about the problems of the rural areas and the urban areas. The urban areas, the half a dozen or so urban areas, that are being crushed by the heavy tidal waive of AIDS cases, are already under that wave, and--I am going to mix this metaphor up--but the rural areas are coming along next, and if we don't do some very prudent thinking about how to deal with the problem in the rural areas, they are going to be as bad off as some of the urban areas.

So I think we need to help those urban areas that are hardest hit, and try to do something to ease the burden that is coming and is already being placed on those rural areas.

CHAIRMAN OSBORN: Ms. Mason?

COMMISSIONER MASON: Hi, Mr. Waxman, how are you?

MR. WAXMAN: Fine.

COMMISSIONER MASON: I was not sure if you addressed this, and it might be that it is just a little bit early for

me yet, and maybe you did and it just slipped by me. But I wondered if the Pepper Commission looked at changing the requirements for Social Security disability, because you have probably heard that lots of people end up dying before they get disability, and that's really a problem in the constituencies that I speak with and travel among.

I have known of cases where people were denied three times, and these are people who are very, very ill, and they had to end up getting a lawyer. So I wondered if that was involved at all in what you looked at, or if you said anything about it.

MR. WAXMAN: Maybe Judy will want to elaborate, but I think our view was that rather than rely on the Medicare program to pick up people who are disabled before that period of 36 months elapses, we would make sure that they weren't left without coverage until that period of time by requiring either that they get their coverage through their jobs or setting up a public program that would give them coverage in the meantime. What we wanted was to make sure there weren't these gaps where people had to hire lawyers and fight to get on Medicare disability because if they didn't get on Medicare disability, they had nothing by way of coverage. We wanted

to be sure that people had some coverage; that there was indeed a true safety net, and that safety net was going to be whole and clear and available to people who needed it.

COMMISSIONER MASON: Well, as you so aptly stated, seven years is a long time for people with AIDS, so I wonder if there is anything that you think we can do as a Commission to kind of expedite some of the processes that would be more life-enhancing for people with AIDS.

MR. WAXMAN: I think the sad reality is going to be until we get a universal health coverage program enacted, we need to recognize that people are going to get their health insurance who have AIDS more likely than not through Medicaid. That's a very sad fact, because in order to become eligible for Medicaid, people will have to have spent their resources to be not just poor, but the poorest of the poor.

I think that is the reality for a while, and we've got to make sure that at least when they get to that point, that Medicaid will be there for them. And then, as we start dealing with the Pepper Commission recommendations and implementing them, to do what we can as quickly as possible to start the insurance reforms, which would be one of the first steps so that employers would not be forced to drop

coverage or fail to cover employees who are HIV infected, but who will have available to them affordable insurance for everyone, because the risk will be spread out among all those who are insured.

Did that touch it?

MS. FEDER: That's it.

CHAIRMAN OSBORN: Mr. Goldman?

COMMISSIONER GOLDMAN: I want to thank you very much for your leadership in so many areas relating to AIDS and HIV infection that you have exhibited. It is an honor to have you here.

I have been one of those who have testified before your Commission, and you are not a member of the committee that I have often thought about would be nice to have in your position--you are not one of those, but it is a pleasure to have you there anyway.

MR. WAXMAN: Thank you.

COMMISSIONER GOLDMAN: Through our travels, we have seen the needs--and you know the needs--of people with HIV infection and the continuum of care that is required. And I am trying to understand, and I find it easier for me to understand in a concrete way if I can figure out what your

proposal would do if fully implemented. Assume a patient with HIV infection required $5,000 worth of AZT and $3,000 worth of aerosolized pentamidine and $2,000 worth of exams and lab tests and physician visits during the course of the year, and some psychosocial counseling at $1,000 for the course of the year, and let's assume one hospitalization for PCP for $10,000, for a total bill of $21,000. What out of that would your plan, if fully implemented, in fact cover?

MR. WAXMAN: Ms. Feder?

MS. FEDER: Some of the services--and I didn't track all of your numbers, and we could do it piece-by-piece--but some of the services are included in the plan, in the recommendations, and some of them are not. The hospitalization, the physician services and lab tests, probably a significant portion of the psychosocial counseling are covered under the Pepper Commission recommendations. The drug costs as Mr. Waxman indicated, prescription drugs are not included in the basic package. However, given the importance attached to drugs by many of the Commissioners, there is a recommendation that as soon as the law goes into effect, that the inclusion of prescription drugs would be assessed under the provision that says that preventive

services should be included as demonstrated effective relative to costs. And it is explicitly indicated that prescription drugs should be immediately assessed for inclusion under that provision.

COMMISSIONER GOLDMAN: So it is mentioned in there about a cap of $3,000 per--

MS. FEDER: That only applies to covered services, so it would not cover the uncovered services.

COMMISSIONER GOLDMAN: Have you done an estimate in terms of cost as to if this proposal were fully implemented, and assuming that it were self-financing, what the annual average premium--I don't know whether you'd call it a "premium", but assuming you would call it a premium--would be for the public plan?

MS. FEDER: The public plan we estimate is about $1,300 per worker. So it is about $1,000 per individual, $2,400 for a family policy. I would want to double-check that number and get back to you, but I believe that's the correct number for the cost of the plan. But the plan is financed by individuals only under certain circumstances. The bulk of the coverage, as Mr. Waxman described, comes through employers, comes through the workplace, and in that circumstance,

the employer pays a minimum 80 percent of the premium, the employee a maximum 20 percent. There is a provision for subsidies to individuals for their share of the premium for individuals in families up to 200 percent of poverty whether they are in private plans or in the public plan.

I think that covers the subsidy.

CHAIRMAN OSBORN: We know that your schedule is tight, Congressman.

I think, David, you had another comment, and Dr. Konigsberg.

Congressman Waxman, do you have a couple more minutes?

MR. WAXMAN: Yes.

COMMISSIONER ROGERS: Congressman Waxman, let me just echo the comments of my follow Commissioners. It is a privilege to have you here. I want to follow up a little bit on Ms. Mason's gentle query to you of the seven years. As you are as vividly aware as any of us, the need right now is absolutely compelling. I guess my question is--well, one a comment, and two, a question.

The first comment is I think the evidence is also overwhelming that if we put the dough in now, it will be

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vastly less expensive than putting it down the way. We'll pay 100-fold over if we fail to begin to address the epidemic right now.

My query: Do you have enough ammunition? Do you have that kind of evidence--and maybe I should ask Judy--that you can put before your colleagues in terms of saying, look, if we fund this now, here is what it will cost; if we delay this, here is what it will cost--which is going to be 10X that time. It is penny-wise and pound-foolish.

MR. WAXMAN: We have held hearings on the matters. We have a record. Let me request of this Commission that you look at the proposals that we are offering for this year on Medicaid and the grant programs and give us your thoughts about those recommendations and whether you think there is a record sufficient from your investigatory work to make the case.

I think the case is clear. I think the case has been clear for some years that if we weren't willing to put the money into prevention through education and individual counseling that the epidemic would continue to spread; that was an obvious reality, yet we failed to put the money in early enough to take some of the steps that could have been

taken to stop the spread of this epidemic. So we don't always act wisely even when we have the evidence clearly before us.

We are paying the price for that. We were penny-wise, and now we are paying many, many pounds over for that foolishness. We shouldn't make the same mistakes in terms of health care services. We need in a number of areas to deal with the AIDS problem. I only touched the health care services. We do need more education; we do need more research. But in health care services, we do need the opportunity for testing and counseling and early intervention and a way to keep these hospitals going that have such a heavy load of AIDS cases for which they are not adequately compensated, if at all.

CHAIRMAN OSBORN: Commissioner Konigsberg?

COMMISSIONER KONIGSBERG: Thank you, Congressman Waxman.

What I'd like to do is just kind of reinforce a couple of the major points that you made, one being the prevention aspects and the other to touch on the rural as well. Certainly from the rural perspective, in many cases we don't have a system to crumble under AIDS; there is not a

system at all. So what I am hopeful is that any legislation from the Federal perspective will help with system development in the rural areas so that we can in fact provide a wide range of services for a person with AIDS in a Linsport, Kansas or someplace of that nature--and I know that Congressman Rowland has some of the same problems in rural Georgia. So I am really pleased to hear that you have picked up on that particular issue.

The prevention issue, as a public health person, of course, is of critical importance to those of us in State and local public health, and I think it is increasingly important that we try to deal both with the primary prevention, which is preventing new infections in the first place, as well as secondary prevention, preventing the complications from HIV, and linking this not only with the public sector health care system but the private as well. Somehow we have got to get the physicians in this country involved with the public sector in this in a joint endeavor. So again, I really commend you for picking up on both of those issues.

Thank you.

CHAIRMAN OSBORN: Dr. Rowland, you had a few more words?

COMMISSIONER ROWLAND: Well, we kept on talking, and finally I thought of a question here that I wanted to ask.

I have been asked this question before, and I think probably all of the Commission have. Our focus here, of course, is on AIDS and what we need to do there, and I get asked this question occasionally: Well, we really need to do something about AIDS, but we don't want to do anything to damage research or lessen the concerns about heart disease and cancer. We don't want to be taking away from that.

So as a Commission, can you give us some idea about how you think we ought to answer that question or deal with that question?

MR. WAXMAN: In the area of research, while there has been some speculation that perhaps AIDS research was taking away from research in other areas, I think the overwhelming consensus is that the AIDS research is benefitting all areas because of the new topics that are being pursued which have application far beyond AIDS itself.

I do have to admit that in the Centers for Disease Control activities I think there has been a shift of personnel and emphasis away from other transmittable diseases and that that has been a shame. We should be increasing the budget

for the Centers for Disease Control to do their job.

I think perhaps the same comment could be made about the FDA, where they have been understaffed and under-funded to take on all their responsibilities, and then they had to deal with the AIDS epidemic on top of all of that. And they have tried as hard as they could to deal with the crisis of AIDS by getting drugs out and available as quickly as possible even before final approval.

So I do think in the research area that additional funding for AIDS research has not detracted from other areas, but helped; but in other governmental activities dealing with AIDS, we have robbed Peter to pay Paul, and that is not a wise thing to have done.

COMMISSIONER ROWLAND: I think you gave the right answer.

Thank you.

CHAIRMAN OSBORN: Thank you so much, Congressman Waxman.

MR. WAXMAN: Thank you.

MS. FEDER: If you have any more specifics--otherwise I can just offer my assistance if you'd like it.

CHAIRMAN OSBORN: We'd like to take you up on your

offer of continued assistance, and we very much appreciate your being with us this morning.

I also appreciate Dr. Kleber's patience in having waited, and I think that we should go on now, but we will be back to you, I am sure, Dr. Feder. Thank you so much.

MS. FEDER: Okay, fine. Thank you.

CHAIRMAN OSBORN: Dr. Primm, I guess, has not yet arrived, but we are very pleased that Dr. Herbert Kleber is with us, Deputy Director for Demand Reduction in the Office of National Drug Control Policy.

As Dr. Kleber knows from conversations and from written communications from this Commission, we have had an ongoing interest that was initially expressed strongly by the Presidential Commission on AIDS in the whole area of drug treatment and so forth, but the interface between the two epidemics of drug use and of AIDS is so important that we want to get a chance to discuss those several issues fully.

Also, having mentioned the Presidential Commission, we want to welcome again Dr. Burton Lee, who is able to take some time with us; we are very glad you are here, and when Dr. Primm arrives, we'll be glad to have him join us.

Dr. Kleber?

STATEMENT OF DR. HERBERT D. KLEBER, DEPUTY DIRECTOR FOR DEMAND REDUCTION, OFFICE OF NATIONAL DRUG CONTROL POLICY

DR. KLEBER: Thank you, Dr. Osborn, and thank you for inviting me to be here.

I thought what I would do is start by just very briefly describing our overall drug control strategy and then be delighted to engage in any question and answer, any dialogue, with the Commission members.

Our office has been charged under the Anti-Drug Abuse Act of 1988 with developing a drug control strategy and then overseeing its implementation. The strategy attempts to be a comprehensive one that deals with both supply and demand issues. It is one of the only ones to have done so in the last decade that doesn't say we're going to solve this either by treatment or prevention or by interdiction or by crop substitution, but says really, if we are going to really do something in this war on drugs, we have to make advances on all those fronts.

Our particular office, the Office of Demand Reduction, is charged with those activities of the strategy that have to do with reducing drug use via demand reduction

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activities--namely, treatment, rehabilitation, prevention, education, et cetera.

What I'll do is very quickly say what we are trying to do in those specific areas, namely, prevention and treatment, and then we can have some dialogue.

In the treatment area, we are attempting to do two things at the same time. On the one hand, treatment needs to be markedly expanded. We feel that these waiting lists that are out there in many places need to be taken care of; treatment needs to be more available. And in FY90 and FY91, there has been approximately a 70 percent increase in Federal funding for treatment.

On the other hand, we are also too much aware of the problems in the treatment system and the difficulties that make it very difficult just to expand it without improving it.

There are problems in expansion such as difficulties in finding sites, the NIMBY syndrome, so that even our former First Lady was unable to open up a therapeutic community in California. There are problems with trained staff and finding adequate staff, and the compensation in most programs is totally inadequate to the needs. We are pledged to devise

ways to try and get around that.

However, we also have out there a treatment system that, although it works, does not work as well or as often as it should or as we would like. In order to do something about that, we along with HHS have developed an Office for Treatment Improvement under the ADAMHA portion, and Dr. Primm, its director, will be testifying after me as to what that Office for Treatment Improvement is trying to do.

We have asked Congress to give us legislation that will enable us to have some accountability on the part of the States as far as what they are doing with the Federal dollar. Right now, the money that goes in for the block grant, which is the largest single amount that the Federal Government is putting into treatment, goes to the States, and there is relatively little accountability back to the Federal Government.

As I travel throughout the country, the most frequent complaint I hear is at the local level, from mayors, county commissioners, et cetera, about the problems they have in getting their fair share of money from the governors. Our hope is that we can get that legislation, which did pass both Houses, but did not emerge from the conference committee,

that it would enable us to require States to develop a needs assessment in the State and then show how the Federal money would be directed toward solving those needs.

We need centralized treatment evaluation units. Right now, what treatment you get is an accident of what door you knock on. That is a dreadful way to run a treatment system. It is expensive, inefficient; it often means that too many people get expensive inpatient care, which not only does not help many times, but then uses up too much of a share of the drug treatment dollar.

In a rational system, there would be an evaluation unit that would take into account what are the needs of the patients; does the patient have psychiatric needs, in which case you then need to have programs that can deal with dual diagnosis. Does the patient have serious medical problems--and in the era of AIDS, increasingly patients have not just HIV but because of the HIV, they are more susceptible to other conditions. So what we saw in New Haven and what I see elsewhere across the country is a marked rise in other infections among these patients. There has been a sharp rise in tuberculosis and the sexually transmitted diseases. So drug treatment programs, much more than they ever have been

in the past, need to have the medical sophistication to deal with this, and very few of them have such sophistication. So we want more comprehensive programs along that line.

We need programs that can deal with habilitation instead of just rehabilitation. A lot of our patients need not rehabilitation, but habilitation. Here we need a program that assesses what that patient needs and tries to refer them to the best program. And we need program accountability.

A recent study by Dr. John Ball at the Addiction Research Center, of six methadone programs found that Program A, 90 percent of the patients were no longer using intravenous drugs, whereas in Program F, only 45 percent were no longer using intravenous drugs.

There are a number of reasons for that discrepancy, but in essence what we say is the States need to hold those programs accountable, that the Programs F of this world need to get appropriate technical assistance, and if they can get their act together, great, and if not then money should be taken from them and given to programs that can do the job.

In terms of AIDS transmission, we know that if a person is in treatment but is continuing to use illicit drugs, especially by the intravenous route, they continue to

run the risk of contracting the HIV virus and of transmitting it to others. And those of us who have been running drug programs--and I have been doing that for a little over 22 years--also know that drug use is contagious. So if you let patients continue to use illicit drugs while they are in treatment, it makes it much harder for the other people in treatment not to use.

So programs need to have appropriate policies, appropriate ways of dealing with that in place, or we are simply going to have a treatment system where too little happens, and people think that something is happening, and it is not.

A final word on the treatment system. Too much of it is currently geared toward heroin and alcohol, when increasingly the problem is cocaine and crack. Most of the treatment programs do not know how to deal with cocaine or crack. And while we need to keep the heroin system in place--and in fact, one of my unfortunate predictions for the early Nineties is we are going to have a marked upsurge in heroin use that we can't dismantle, then, and probably in fact will need to expand it. We certainly need to expand the opportunities available for the treatment of cocaine and crack,

and we need much better research to develop better methods for those drugs, because right now in many cases, we don't know how to adequately treat them, and we know that in addition to the spread of AIDS through intravenous drug use that in certain areas, San Francisco being one of them and New York another, that we are getting an increase in transmission of the HIV virus through the sex-for-crack phenomenon.

Let me turn next to prevention. It is very important to do treatment. But we are not going to get anywhere in dealing with drug abuse unless we also deal with prevention.

When I left New Haven, we had 1,000 patients a day in treatment. A few years earlier, we had 800; a few years before that, we had 600. It was very clear to me I could probably have gotten 1,500, maybe 2,000, in treatment, and that is in a city of 150,000 or so population.

So we need to do something about prevention; otherwise the number of people just coming in for treatment will continue to spiral out of control.

Prevention is twofold--one, helping those individuals who have never started not to start, and helping those who are started but not yet in trouble to stop. We

have a number of strategies on that involving the school, the workplace, focusing on user accountability. What we say is that the vector of the problem of drug use is not the addict; the addict is not the role model for anyone including himself. The role model for addiction, for drug use, is the casual user who, by their behavior, gives the message that you can enjoy the effects of drugs and still keep your job, your health, your material possessions, et cetera, and that person in a sense spreads the contagiousness. Most people start drugs not by getting their drugs from some pusher in a dark alley, but by getting it from a peer, a classmate, an older sibling, and increasingly by a fellow worker on the job. So by focusing on the casual user via school programs, via workplace programs, we hope to decrease the number of people entering that pipeline.

And finally what we say in this strategy is that this is not a Federal strategy. This is a national strategy. The only way this is going to be effective is if we can enlist the cooperation of people at the local level. My colleague, Dr. Musto, from Yale, in looking at what happened in the last cocaine epidemic at the turn of the century, noted that the only way that was handled ultimately was the

coming together of all the various facets of the community--the parents, the religious community, the health community, the law enforcement community--and that is what we are trying to do at the community level with community development grants, et cetera.

So let me close on that note. I could go on--I could clearly spend all the time describing the strategy. It is a long one; we have already put out two volumes on it. But let me stop at that point and open this up to dialogue.

Thank you.

CHAIRMAN OSBORN: Thank you very much.

Dr. Primm, do you want to join us at the table, or shall we do this seriatim? Either is fine. Dr. Primm has joined us.

DR. PRIMM: I could sit with Herb; he doesn't mind.

DR. KLEBER: The danger, Beny, is that I am very good at referring questions.

CHAIRMAN OSBORN: That's what I was thinking about.

I want to welcome Dr. Beny Primm, Associate Administrator of the Office for Treatment Improvement of the Alcohol, Drug Abuse, and Mental Health Administration. Thanks for joining us--you are just in time to handle the

questions for Dr. Kleber.

DR. PRIMM: Well, thank you.

CHAIRMAN OSBORN: Do you want to do it in that order, or would you prefer that Dr. Primm talk, and then we can--

DR. KLEBER: Well, I'm going to have to leave, so I think if there are specific questions directed at me, because I have a 10:00 meeting at OEOB, I would be delighted to answer questions now.

CHAIRMAN OSBORN: Okay, fine. Let's do it that way. Larry Kessler?

COMMISSIONER KESSLER: Dr. Kleber, could you elaborate a little bit on what you mean by focusing on the casual user? Are you talking about education or penalties, law enforcement, or whatever--because I'm concerned about the issue of denial among that group and who their peers are. Certainly they are not looking toward the addicted individual, or the highly addicted individual who is out of work and perhaps engaged in some criminal activity or whatever.

How does that strategy work?

DR. KLEBER: It is segmented into two groups--the

adults and the adolescents. Most so-called "casual users"--and by the way, I apologize for that term. It is a dreadful term. In writing the strategy we agonized between five equally unacceptable terms--"casual user", "controlled user", "recreational user", "nonaddicted user". The point is to basically come up with a dichotomy--those individuals who are addicted, and therefore by definition need treatment, and those who by definition can control their drug use because they are not addicted. Therefore the so-called "casual" or "controlled" user.

And since by definition we are saying that these are people who can control their use, and if not, then they call into the other category and require treatment, they need to be held accountable for that use. Therefore, we encourage workplace policies, because we know that most people who use drugs are employed; most people who use drugs are not poor; most of the drug users are white and a part of the majority culture. Most of the poor are not using drugs. So that by workplace policies that say if you use drugs, you may lose your job, through testing procedures that bring that about, through employee assistance programs for those who need help in doing that, we try and hold that casual user accountable

for the use, hoping that they will stop, because the sanctions are such that the drug use is not worth the loss of the job.

The same with adolescents. We know that education is very important. We also know that education is not sufficient. William Raspberry put it very well when he said that "Education is a cure only to the limited extent that ignorance is a disease." Unfortunately, too often, ignorance isn't a disease. Adolescents know perfectly well what drugs can do. They also know it is not going to happen to them. So you need drug education, but it has to be comprehensive, and there also have to be firm policies in the schools that say if you use drugs, we will suspend you; you will be required to bring in your parents; you will be required to attend certain kinds of counseling, and if you do it again, we will expel you, and you will have to attend alternative schools.

So that is what we mean by that kind of user accountability and focusing on the casual user, that individuals will be held accountable for their drug use.

CHAIRMAN OSBORN: I'll take questions in the order we saw hands: Don DesJarlais, Harlon Dalton, Diane Ahrens, and Roy Rowland, Don Goldman, and others.

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COMMISSIONER DESJARLAIS: Two questions. The previous Presidential Commission recommended ready availability of treatment, treatment on demand, in the sense that someone would be taken into treatment on the day he or she applied for treatment. You wrote an op ed piece in the *Times* pointing out that that clearly would not solve the drug abuse problem, and it would clearly also lead to additional expenses in that you would have to have some percentage of excess capacity for people who might come in on a particular day.

Given the focus of this Commission on AIDS, would you make exceptions to your general opposition to ready availability of treatment for people at very high risk of getting HIV infection, specifically people who are injecting drugs and perhaps even people who are using crack and engaged in unsafe sexual activities, because there the financial argument anyway would not seem to be particularly applicable, because if they do get infected with HIV it is going to cost so much more.

DR. KLEBER: There are a number of ways of addressing that. One, in general, those are the people who are coming for treatment anyway, the intravenous users, the

cocaine and crack users.

The block grant has a 50 percent i.v. set-aside, so that States need to show, unless they ask for a waiver--in New Hampshire, where they may not have many i.v. drug users, they ask for a waiver--but in States where there is a high percentage of i.v. drug users, that increased Federal money in the block grant should be going toward expanding capacity for the i.v. drug user and for expanding capacity for the cocaine user. In many places, the issue is they don't know what kind of treatment to do for the crack users.

We are hoping within the next few months to be announcing a treatment campus initiative to try and markedly increase residential capacity so that especially for the cocaine user, where outpatient treatment is often not as effective as it can be for the heroin user.

Also, there are a lot of problems in the system. I was told yesterday, for example, that in your State of New York, none of the waiting list money has yet gotten down, really, to the streets. In fact I think the program that you are affiliated with is supposed to get close to $1 million for its waiting list, and I don't think it has gotten a penny of that yet. Whereas in New Jersey, I think the waiting list

money is already out to all the programs and is treating people. So that those kinds of problems need to be resolved.

Also, New York City and other places like that should be setting up centralized referral units. When I went with Dr. Bennett to New York in June to visit treatment programs, the day we visited Dr. Primm's program, for example, he had a number of vacancies in his program, and his staff had called around that morning and found there were over 400 vacancies in methadone programs in New York. Now, that's not a large number. That could even be a sort of dynamic kind of vacancy rate in a system that has over 30,000. But there should be some sort of central telephone number or something that can tell patients where the vacancies are and how to get to them and let programs know, so that counselors are not sending patients out on the street when programs down the street may have vacancies.

That won't solve all the problems, but at least it will help with some of the structural difficulties in getting treatment.

So I hope that as we markedly expand the size of the system that this will take care of the difficulty in these high-risk patients getting treatment.

COMMISSIONER DESJARLAIS: I take it, then, you do believe that immediate treatment on application is a worthy goal for at least people at very high risk of HIV infection?

DR. KLEBER: Well, I think the word "immediate" is where we get into difficulty. My experience in the late Seventies when there was that--most of the methadone programs, for example, were running 20 to 30 percent vacancies in the late Seventies--and what you found was a much greater revolving door. That is, if the addict is so impulsive that if he comes in for treatment on Monday and there is no slot, he may not return for three to four months. The problem is that same addict is just as impulsive on Wednesday, and if he knows that there is treatment available all the time, the likelihood is he is going to drop out in a few days, knowing he can come back next week.

What we found in the late Seventies was that with that system, there was just a speeding up of the revolving door. So what I would like to see is much readier access to treatment. I would disagree with the word "immediate", but certainly much quicker than currently. But at the same time, the "carrot" of the readier access being balanced by some method of holding people in treatment. And we are exploring

that. We have set up now a group to look at the whole issue of civil commitment, to look at if these high-risk individuals enter treatment, it shouldn't be so easy to drop out the next day. There should be some way of saying "You've got to stay in for a while," because otherwise they don't do themselves or the rest of society a favor by just treating treatment as a revolving door.

I mean, if treatment were so good that we could capture and successfully treat 80 or 90 percent of the people who came in, then I would say, hey, let's have it immediate, and we don't need those things. But the reality is that the nature of addicts is such that their goal and the goal of the treater is often very different--the treater wants them to stop all drugs. What the addict wants to do often is return to the "honeymoon" period, where they can use drugs on a controlled basis and not in an addicted fashion, and they keep trying to return to that "honeymoon" period.

COMMISSIONER DESJARLAIS: One follow-up question. You mentioned many of the difficulties in getting people to stop using drugs, particularly heroin and cocaine and alcohol, when they come into treatment. Given these difficulties in treatment as well as successfully completing treatment

at least of one episode, what do you feel the country should be doing to prevent HIV infection among people who either do not come into treatment, try to get in but can't get in, or do get in but do not succeed in treatment?

DR. KLEBER: On one leg, or--that's a whole treatment strategy. I think you need different things for those three groups. There is not one answer to that question. For those that are not interested in coming into treatment at this point, there needs to be more in the way of outreach activities.

ADAMHA has a number of initiatives, for example, in the AIDS outreach program. In fact, when I left New Haven, we had one of the NIDA grants on that--we had a mobile unit that went into areas of high drug use; we had street workers that distributed bleach, that encouraged people to come in for detoxification if they weren't willing to come in for any other kind of treatment. So I think that that kind of outreach can try and bring some of the people who aren't interested in coming into treatment--that may be one of the first kinds of contacts with the treatment system and may get them to come in.

For those that come in and drop out, I think I have

already indicated it is a difficult thing. We are looking at various kinds of legal maneuvers that may be of help with that. And for those that want treatment, come in, and there is no immediate access, our hope is to raise the size of the treatment system. As I said, there has been a 70 percent increase in Federal funds for this. In 1987, the treatment system--and I apologize for such an early date, but one of the things I found when I took this position was the extraordinary inadequacy of the data base--in 1987 the system was able to treat in any given year somewhat over 800,000 addicts. We hope that by 1991, we will be able to treat 1.7 million, roughly double the number from '87. And again, that won't be enough. But we are getting closer, and certainly we will be back, asking for additional funds for treatment to try and expand the system.

My hope is if I can improve that infrastructure that we will be able to then do much greater increases, Congress willing. It will depend on the willingness of Congress to give us the funds once we have that infrastructure in place.

CHAIRMAN OSBORN: As I mentioned, there are several other Commissioners that I know have questions--Harlon,

Diane, Don, and Dr. Rowland--I know you have a time schedule, and we'll try and accommodate that.

Harlon Dalton?

COMMISSIONER DALTON: Actually, I have a quick question and then a longer observation. The quick question is what are you doing about getting business express or U.S. AIR to start flying into New Haven again, since you have an interest in that?

[Laughter.]

DR. KLEBER: Our powers are great, but not that great.

COMMISSIONER DALTON: My observation really builds on Don DesJarlais' question. The editorial in the New York Times in January about treatment on demand--if one reads it, leaving aside the question about the need for excess capacity, the rest of your arguments essentially against treatment on demand are very much like your testimony here today--namely, that we need improvements in the treatment system, which is why Dr. Primm is sitting next to you; that we need to focus on cocaine and crack rather than so heavily on heroin; that we need--

DR. KLEBER: Or as well as; in addition to.

COMMISSIONER DALTON: --as well as, yes--that we need additional treatment slots, et cetera, et cetera, all of which I suspect most of the Commissioners would agree with you--I don't see those necessarily as in opposition to treatment on demand. So what I am really concerned about is the packaging. It seems to me that you use the hook of treatment on demand and the opposition to it as a way of making a case for improving treatment, as a way of making a case for making States more accountable, as a way of doing all the things you talked about today, all of which are laudable, but what worries me is to do that within the framework of opposing treatment on demand I think is really very hurtful. It seems to me that in a sense, the opposite of treatment on demand, or the message that one conveys when saying "I am opposed to treatment on demand" is that if an addict does present himself or herself for treatment and is in the frame of mind or the frame of body to take advantage of it, we are not going to say yes. And I think we need to move this aside to the point of realizing that we don't have available the resources to deal with those addicts who want and are capable of taking advantage of treatment. I think that message gets really blurred when you use the issue of

treatment on demand as a way of making all these other points, which need to be made, but I think maybe not by taking down that particular flag.

DR. KLEBER: Yes, I understand your point, and it is a good one. The problem is that so often treatment on demand has become a shibboleth, an easy answer to our whole drug problem, just like the advocates of legalization say, well, if you only legalized drugs, that would solve it--that's another easy answer that, when you examine it in detail, falls on its face and in fact would be an absolute disaster.

COMMISSIONER DALTON: But when Don Des Jarlais says treatment on demand, you can't believe that he doesn't understand the kinds of complexities that--

DR. KLEBER: No; I agree, Harlon. What I'm saying is that we can't afford in the treatment system the equivalent of the military $500 pipe wrench. When I had my confirmation hearing and made my courtesy visits beforehand, some of the people who I met asked, "Why aren't you asking for more money for treatment?" and about an equal number said, "You have a hell of a lot of nerve asking for the money for treatment you are asking for when it is so clear that treatment doesn't work."

And I think that we need to be very careful in treading that middle ground that says in essence treatment can work, but if we simply throw money into current treatment systems, what we are going to have in Congressional testimony a few years from now is the equivalent of what the Pentagon has, in which people are saying: "You spend a lot of money. What can you show me for it? What's your success rate? What's happening?"

So I don't disagree that we need to have treatment occur much quicker than it does now, and I really don't want to be sparring with words, "treatment on demand" versus "quick treatment" or whatever. Certainly I don't want the waiting lists that we have now. And if by that you mean that within a reasonable period of time when someone applies for treatment they should get it--absolutely--along with a way of, once they get it, some way of making it a better treatment they get into and of holding them into it.

There is no easy way to do that. Treatment is very labor-intensive. The treatment people I talk to out in the field say you probably can't increase the capacity of the treatment system much more than 25 percent a year; it can't absorb it in terms of the infrastructure that's out there.

That doesn't mean in any given place you might not be able to increase it by 50 percent, but overall as a system, you can't increase it by much more than 25 percent a year. And that's what we are up against.

So I don't want to denigrate treatment by fighting against treatment on demand; I don't want to say treatment doesn't work, and you shouldn't fund it. I am an advocate of treatment. I have spent my whole professional career treating patients. I believe in it. I know it works. I also know from traveling around the country that a lot of what passes for "treatment" out there is not very good and needs to be sharply improved.

CHAIRMAN OSBORN: Commissioner Ahrens?

COMMISSIONER AHRENS: I just have two comments, and I thought they might be of some value because at the risk of riding a dead horse, I want to get back to this issue of treatment on demand.

What I heard you say was that you are really coming at the issue of funding more on a grant basis than a categorical basis, so that people will have access to a system regardless of where the money had been formally. If that's what I understood you to day--

DR. KLEBER: I'm not quite sure. There are two ways we are trying to increase the capacity of the treatment system. One is through expansion of the block grant, which is the main mechanism by which the Federal Government contributes to treatment in this country. The other is through treatment demonstration projects, a lot of which will be flowing out through Dr. Primm's operation. That is, if we need a treatment program for pregnant addicts, it may not be enough to simply increase the block grant; what we need to do is have some treatment demos that show the country here is what a system for treating pregnant addicts looks like, because in many places they don't know how to do it, and in fact, we don't know enough in general about how to treat pregnant addicts. So the OTI will be putting out those kinds of treatment demos about pregnant addicts, about crack addicts, et cetera, treatment campuses, that sort of thing, so that there will be those two ways.

Now, under the block grants there are those set-asides. There is a women's set-aside, and there is an i.v. set-aside. But that remains part of the general kind of funding mechanism which would not be called I grant mechanism, I wouldn't believe. Grants in general for treatment are more

in the research, and they are given by NIDA.

COMMISSIONER AHRENS: Let me pursue this just a little further. From where I sit and where I come from, we have something called a consolidated fund, and the States allocate to counties the money for treatment on a consolidated basis so there are no longer the categorical kinds of funding that we used to have.

What we have been able to do because of that is to make the best use of the dollars and see that people do get access to programs. And it really almost totally eliminates any kind of abuse in the system that you are concerned about if there were to be treatment on demand, because a team approach is used, and people are placed in the appropriate treatment, and of course, because we want to maximize our dollars, we use very little residential treatment, and it is only done under this sort of team approach. So I think what that does when it is given that way is to minimize any abuse in the system because we want to use those dollars and squeeze them as much as we can. And I think that if that is the approach that you are beginning to use federally, that it will really make fairly irrelevant the issue of abuse in the system.

DR. KLEBER: Certainly one of the reasons we want those State treatment plans is to be able to look at if in your State that is working, and if that's where the patients are, that's where the money should go. Unfortunately in too many States--in Pennsylvania, Philadelphia may have 45 percent of the drug addicts and get less than 30 percent of the funding--those are the kinds of abuses that are in the State systems. I am glad to hear--I don't know what State you are in--

COMMISSIONER AHRENS: Minnesota.

DR. KLEBER: --Minnesota--that in your State, the block grant method seems to be working, and I am delighted to hear it. But we need more of that.

COMMISSIONER AHRENS: And I'd just like to say that in terms of cocaine and crack abuse, our county has resorted--I don't know if that's the right word--to we are experimenting with acupuncture; we just don't have anything.

The other thing--

DR. KLEBER: I would just caution you on that, to really take that word seriously, "experimenting". I have looked at the acupuncture literature, and as far as I know, there have been no controlled studies. It is one of those

things that seems promising, but no one has done an adequate controlled study to see whether it actually works. And again, with our scarce treatment dollars, I would hope that people are actually studying this. The one paper I saw on acupuncture said that 50 percent of the people still in treatment at three months had cut down their drug use--which said nothing about how many of the people had started, and what did they mean by "had cut down"--and was it 50 percent of 100 percent, or 50 percent of 10 percent. So that you really need in the treatment system to have controlled studies. There have been too many "cures of the month". I usually juxtapose a 50 percent success for acupuncture with a 70 percent success of the monastery in Thailand, which has the same kind of follow-up statistics.

COMMISSIONER AHRENS: We'll let you know.

DR. KLEBER: Please. We would be very happy to.

COMMISSIONER AHRENS: I had just one other comment that I'd like to make--

CHAIRMAN OSBORN: We are running very short of time, and I have several others--if it's very quick--

COMMISSIONER AHRENS: Well, I just want to say that as you gentlemen have access to the powers that be, I think

what you need to know is that what is happening across the country at the local and State levels with respect to the rhetoric that is very pronounced at the Federal level regarding drugs and the lock-up mentality, is that the impact around the country is very severe. In my county, 75 percent of the increase in our budget this year went to the criminal justice system. Now, that is eating up all of our resources for all of the other things that we have to do, including all of the health services that we have to provide.

So I hope that kind of thing will begin to percolate up to those who seem to feel that lock-up is the answer, because it is impacting all of our systems, all over the country, not just at the Federal level.

DR. KLEBER: What we would hope is a good coordination between the criminal justice and the treatment systems. There have been a number of studies, for example, showing that people who come to treatment involuntarily do just about as well as those who come to treatment voluntarily. And if people are arrested for drug use or for activities related to procuring the money for drug use, it doesn't mean they have to go to jail. They can be compelled instead to go into treatment, but what we would hope would happen is that that

system would really work, and if they were compelled to enter treatment as they dropped out, they would be told "treatment or jail", and if they dropped out, jail would be an option. My experience has been that if you do that, patients do quite well; if you don't do that, then the system becomes a joke, and the dropout rate becomes very high.

CHAIRMAN OSBORN: Dr. Rowland, you have been waiting patiently, and I think I'd better let you go ahead.

COMMISSIONER ROWLAND: Thank you.

Since the great increase that we have seen in sexually transmitted disease including HIV is related to the drug abuse problem, and they are so tied together, anything we see occurring in an increase in drug abuse is of great concern to all of us. I was in Southeast Asia in January of this year, and you have already referred to the increase in heroin, and there doesn't seem to be any activity at all there to reduce the export of heroin from the Golden Triangle--Burma, Laos and Cambodia--it is very much a part of their economy there, and even in Thailand, they are really struggling with trying to deal with this, and they are projecting a significant increase in the export of heroin. You have already alluded to that. And since drug addicts are mixing

CNS depressants with CNS stimulants now and methamphetamine is going to be a CNS stimulant that we are going to see increasingly used, I believe, I'd like to hear your comments on how are we going to deal with this. Crack cocaine, it seems to me, is going to fade out, and we are going to see more methamphetamine, since it is going to be so easily obtained apparently in this country.

Would you comment on that?

DR. KLEBER: Yes. I was in Hawaii in December to look at what is going on there, with their "ice", which is a smokable methamphetamine problem. My own prediction--and I could be wrong--but my own prediction is that we will not have an "ice" epidemic for a number of reasons. I think that, one, the country is not ready for another stimulant epidemic. If "ice" had come along in '85, we might have had an "ice" epidemic instead of a crack epidemic. But I think the current stimulant epidemic is running its course, and what we will see instead with "ice" are pockets of it across the country similar to PCP. So that in Washington, we have a major PCP problem whereas in Baltimore, we have very little PCP. My expectation is we will see that with "ice". San Diego will have an "ice" problem. It has been the metham-

phetamine capital of the United States for many years; they are going to have an "ice" problem. There will be some others, but for many addicts, as I talk to them on the streets, "ice" has a vice of its virtues--that is, it lasts a long time, and many addicts prefer the much quicker up and down of a drug like crack to the eight-hour or so duration of "ice".

So we will have an increase in "ice" but I still stay with my prediction that the major problem in the first half of the Nineties is not going to be "ice" but is going to be heroin, for some of the reasons that you mentioned. I think the supply side of heroin that we are seeing now is equivalent to what we saw with cocaine in the Eighties, that is, an overwhelming abundance of cheap, high-quality heroin, the likes of which we have never seen before.

When I left New Haven, street purity of heroin had already risen to about 35 percent whereas traditionally it was about 7 to 8 percent. And I think we are just ripe for that. That is why it is very important in the treatment system and in prevention that we don't lose sight, while we concentrate on cocaine, of heroin, and I am trying very hard to keep that heroin system in place and expand it because we

are going to need it.

CHAIRMAN OSBORN: Don Goldman and then Eunice and David--and then you have to go.

DR. KLEBER: Yes, thank you.

COMMISSIONER GOLDMAN: Dr. Kleber, I assume you agree whole-heartedly with the statement that making sure treatment is available so that people seeking help won't be turned away is a priority, is a correct statement of your policy and the Administration's policy.

DR. KLEBER: Although we could quibble on the meaning of some of those words, I would say in general our policy is yes, we want to markedly expand treatment to make it available when patients need it--which is not quite treatment on demand.

COMMISSIONER GOLDMAN: This is a direct quote from Dr. Bennett's most recent report--

DR. KLEBER: Yes, absolutely, and I helped to write that--as long as we agree on what it means.

COMMISSIONER GOLDMAN: He said that making sure treatment is available so that people seeking help won't be turned away is a priority.

DR. KLEBER: That's correct.

COMMISSIONER GOLDMAN: One could talk about what it means. I don't think "being turned away" is a very difficult concept. But assuming that's correct and assuming it is a priority, why isn't it appropriate to set up explicitly as the Presidential Commission did, understanding all of the caveats that you had mentioned and understanding the problems of NIMBY-ism and understanding the capacity problems of setting up the idea of what some people call treatment on demand, what I call making sure treatment is available so that people seeking help won't be turned away, as a matter of a proper, appropriate, national, long range goal, and why can't Dr. Bennett and your office help set up a goal and a timetable that we can achieve and set a two- and five- and ten-year goal and say that in ten years we ought to have a system, or in seven years, or in five, that we ought to be able to develop the capacity on a national basis to have a system whereby people seeking help won't be turned away?

DR. KLEBER: Well, there are a number of problems with that. For example, I got a call from a reporter yesterday saying, "I noticed that in your strategy you didn't give any goals for what the reduction of heroin use in ten years is going to be. What do you expect it is going to be?"

And my feeling at this point is I'm not prepared to in any way address that because given what I've just said about the increase of heroin in the Nineties, it would be irresponsible of me at this point to make predictions about where heroin is going to be and likewise to be able to say that in five years we are going to have adequate treatment for every heroin addict that needs treatment, when it is going to be hard for me to know in 1990 how many heroin addicts need treatment in 1995. It is a wisdom that I don't think we possess in the Federal Government or indeed in the private sector.

I would like to instead see--and this may simply be a matter of fighting about rhetoric. I am pledged to a marked expansion of our treatment system both in quality and in quantity. And you have my commitment on that. I want a major expansion. Dr. Bennett is on record as wanting a major expansion. The President has signed onto the strategy. This is his strategy.

So I would hope we would not get bogged down in fighting about the rhetoric of whether this marked expansion is the same as treatment on demand because I don't think that is a terribly useful exchange. It is something that people of good will can differ on.

CHAIRMAN OSBORN: I think we are going to lose Dr. Kleber to his next commitment, and I want to be sure that everybody gets a chance, and we will want to pursue this line of discussion, but I think we can perhaps do some of that with Dr. Primm in just a minute.

Eunice Diaz and David--and if you will indulgence us that far, then we really have imposed on your schedule.

DR. KLEBER: Okay.

COMMISSIONER DIAZ: I have two questions, and one in the form of an observation. The clear message that this Administration is sending particularly through your office is that there is not a clearcut connection between increased drug use and HIV. That just has not been established by either what has been communicated out of the office or out of the Bennett Plan. And I think this is particularly distressful to minority communities of this country, both Afro-American and Hispanic communities, that are not only faced with tremendously increasing numbers of drug users among us, but also a tremendous increase and a higher proportion of people getting infected, new infections, through the drug route. And until we can make that connection--and the force of your office and the White House is such that within this

country we tie the two--HIV infection and drug use--I think we are really beating our heads against a wall.

It seems that if we continue to say the way we are approaching this is through this civil containment, did you call it, civil commitment type of effort or focus and increased focus on the criminal justice mode, it may be really alienating our communities to the point of really not being able to enlist their cooperation, participation, in education, treatment models that are very specific to the problems faced in minority communities of this country.

DR. KLEBER: I certainly believe that drug abuse is one of the major ways that AIDS is being spread in this country now. So let me be very clear on that. There is no question in my mind that as I look at the statistics, that the transmission of AIDS by the gay community has been much less in recent years in terms of being controlled than the change in behavior by the drug-abusing community. They have not changed their behavior, and through them and through contact with their sexual partners, we are spreading the HIV virus. There is no doubt in my mind on that, and if we have not been clear enough on that in our messages, I will try and be clear on that, because it is certainly something that we

are aware of, believe, and that is one of the reasons that we are trying to increase the size of the treatment system to make sure that the treatment is available to do something about that.

The second part of what you were saying, the emphasis on law enforcement, is part of a strategy which says in essence that you don't win this simply by focusing on treatment. The point I made about the increasing number of addicts in New Haven was what I meant by that, that you need to decrease the number entering the pipeline; you need to do more in prevention. Treatment is important, but no war was ever won simply by treating its casualties. We need to prevent people from getting HIV in the first place; we need to prevent people from using and abusing drugs. And in order to do that, we need a combination of law enforcement and prevention activities. One or the other by itself is not going to work. Law enforcement without appropriate prevention activities will not work, as the Attorney General has said, and prevention activities without a stick, a carrot alone, will not work.

My analogy to that is driving. Driver's education is very important. On the other hand, most of us would be in

agreement that if you don't have some state troopers along that highway, there are going to be a lot more cars exceeding the speed limit.

So we certainly want trained and educated drivers, but there also needs to be that reminder of "Here is what will happen if you disobey the law."

Dr. Rogers?

VICE CHAIRMAN ROGERS: Dr. Kleber, thank you for being here.

I think my fellow Commissioner, Ms. Diaz, has expressed part of our concerns. It will come as no surprise to you to know that the members of this Commission were profoundly troubled by the fact that a national drug control strategy could put out an entire volume and not once mention the Siamese twins of HIV infection and drugs--but let's leave that aside.

I think what concerns me about what you have said is that as a physician--as a physician--I know of no other fatal disease in which we say, "Go away; we'll treat you later." And I consider i.v. drug use or crack use a fatal disease. We don't use the excuse of, "We don't know quite how to treat you; you may not behave; you may not stay in

treatment"--we don't do that with people with congestive heart failure. We don't do that with people with cancer. Why we do it with people who have this fatal disease and say, "We don't have enough money to treat you," or what-have-you is to me still incomprehensible. It just shows a very subtle prejudice, and I think it in essence says some bad things to troubled communities, that "You are bad people, and we're not going to put you in treatment." I don't say that to people with cancer, and we don't know how to treat that, but we do our damndest to try and get them in and to do the best we can with them.

And your editorial and some of that, really, I think either attitude you hold is self-reinforcing. If you say these people aren't to be trusted, they won't come into treatment and so on--how do you know until you really offer them that?

DR. KLEBER: Well, I have to respectfully disagree with some of your points. Addiction is not cancer. It is a much more complex interaction of physiologic and behavioral and psychologic components in which the behavior of the individual is a very important part of what is going to happen with controlling the disease.

Now, I recognize that people like Bernie Segal would say the same for cancer. But in addiction, we have no penicillin. We have no way that we can simply stick the individual and say "You are cured." We have no vaccine.

Where we do have agents, we find that it is hard to get patients to take it. In the treatment of heroin addition, for example, we have a drug called Naltrexone [phonetic]. We are one of the pioneers in its use since 1973. It is a beautiful drug. It is everything you would want to treat a heroin addict. In fact when people say we need a methadone for cocaine, what I say is you really don't want a methadone--you want a Naltrexone. Naltrexone is a pure narcotic antagonist. It blocks the effects without being addicting itself. It is long-acting; it lasts three days. There is only one problem: You can't get patients to take it.

In New Haven where we have pioneered it, we have 50 people on Naltrexone and no waiting list; 500 people on methadone and three- and four-month waiting lists. So that even when you have very good methods, it is not getting people in to use them.

I have told people on the waiting lists, "We will treat you tomorrow if you are willing to take Naltrexone"--

heroin addicts waiting for methadone, and they say no. They say, "We want methadone. We don't want Naltrexone."

So that this is a very complex phenomenon, and we don't have many of the answers. That is why we need more research. I don't want to be sending people out into the night who need treatment, but we need to make sure that the treatment we give them does work, because otherwise, as we all know, we are going to go up in front of Congress, and Congress will say, "What's your treatment success?" and when we tell them, "Well, we treated everyone that came to the door, and we had 20 percent who got better," or 50 percent who got better, they are going to say--and they probably won't say it in cancer, but they will say it in drug abuse-- "Well, then, you are wasting the taxpayers' money. Come back again when you have effective treatment," and then we'll provide adequate treatment.

VICE CHAIRMAN ROGERS: I wish we could do that well with lung cancer, and we treat them.

DR. KLEBER: Well, I think this is where, because people perceive lung cancer as, quote, a victimless disease-- even if the individual smoked--there is still much more of a perception that drug addicts are part of the problem that got

them there, and therefore in terms of funding treatment for it, there is still that thing that you need to do more to bring about, to be helpful in your own treatment, and for better or for worse, we know that many of the individuals who have drug abuse are not interested in treatment. It is the nature of the beast. It is part of the complex part of being a human being that many people want drugs to alter their psyche.

We did a study on addicts who were not in treatment about what they knew about HIV. We found that over 80 percent of the addicts knew everything we would have wanted them to know. They knew how it was transmitted; they knew it could be fatal; they knew you could get it by sharing needles with someone, even though that other person looked healthy; they knew about the sexual things--and yet 75 percent of that group indicated they were continuing to engage in that kind of behavior that they had just indicated a few minutes earlier would kill them. The only time they tended to change that was when they were first diagnosed as being HIV-positive. At that point, they then wanted to change that behavior. But as long as they were negative, there are some of the feelings of invulnerability, that "It can't happen to me."

Trying to get addicts to worry about something that is going to kill you in five years, when you can die with the next shot, is a problem in the treatment system.

And I would like to bring you more encouraging news, and hopefully, what you will hear at 11:00 with Dr. Brown about the research that is going on, maybe in a few years, we will have better treatment methods. But right now, that's the nature of the treatment system, and we'll try and improve it, but that's where we are right now.

CHAIRMAN OSBORN: Dr. Kleber, thank you for engaging in a very important discussion with us. I think we will all be working toward a common goal of reducing both epidemics in ways that we see effective. Obviously, there is more that we could talk about but I know your schedule is pressing, and Dr. Primm will talk with us a bit more, so thank you so much for taking the time to come and speak with us.

DR. KLEBER: You are very welcome. Thank you for having me here, and I can assure you that Dr. Primm will be happy to answer any of the questions that I was unable to answer.

CHAIRMAN OSBORN: I was just going to comment that

Dr. Primm holds not only the offices I mentioned, but he also was on the Presidential Commission, so he knows just exactly how interested these Commissioners now are. It is very kind of you both to wait and to be willing to take over at this intense juncture.

I have learned that the coffee will wait for us, and you have been so kind in waiting, that if the Commissioners don't mind, we'll proceed to talk with Dr. Primm and then break after that. I apologize to everybody that we are a little bit late.

Dr. Primm, welcome.

STATEMENT OF DR. BENY J. PRIMM, ASSOCIATE ADMINISTRATOR, OFFICE FOR TREATMENT IMPROVEMENT, ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

DR. PRIMM: Thank you so much.

I would first like to just say hello to so many friends that are among the Commissioners. I just want to say I think you are doing a great job, and although this seat is a hot one, and I have been sitting in that seat over there, and I made this seat hot when I sat over there, so I expect the same from you. But I am happy to be here.

I'd like to begin by telling you a little bit about my office. It is quite different from that of Herb's office in that Herb's office, or Dr. Bennett's office, is responsible for policy and strategy, and my office is responsible for what I think are the good things, and that is improving treatment in our Nation and to carry out or implement some of those strategies and policies. The Public Health Service, of course, of which my office is a part, is about that.

I don't want to go into all the problems and recite them for you because I'm sure all of you know the problems around drug abuse, and I'd like to say "drug abuse" rather than "intravenous drug abuse" as a contributory factor to HIV

infection. Drug abuse in general is, and I think all drug abuse is, and not necessarily just i.v. drug abuse.

I treat it like that at OTI or the Office for Treatment Improvement.

What are some of our initiatives? Well, you know that the block grants have been increased since 1987 to 1990 by 160 percent. My office is responsible for administering the block grant program, the ADMS, the Alcohol, Drug Abuse and Mental Health Block Grant Program. And I am very proud of the fact that we get our block grant moneys out timely to the States. Right now, we are trying to do our damndest to see that the States get that money out quickly and timely, of course, to the providers of service, and that is a very difficult job.

I just left Puerto Rico, and the Virgin Islands and much of the block grant dollars have not yet left the State coffers and gotten to the providers.

We also were responsible for distributing the waiting list dollars, of which $100 million were allocated in 1990. I am happy to say by April 2nd of this year, all of those dollars will have been sent to the States, and the requests will have been fulfilled.

I am shocked, though, to note that in New York City and in other States, Puerto Rico and other States and Territories, that the moneys from the waiting list dollars have not filtered down to providers. For example, my colleague Dr. Kleber talked about New York City and the request for about 543 treatment slots for one of the institutions in that city that always reports a waiting list for intravenous drug abuse treatment and their methadone maintenance treatment programs. They requested a total of about $929 million, and not one of those dollars has filtered down to that treatment program. That shocked me. It shocked me because number one, many other programs in New York City have received their money; many of them are already spending their money, expanding treatment services, or have taken the patients off their waiting lists who were on their waiting lists, and they are right now in treatment. That institution has not.

There are other institutions--it is not by itself--that have requested $5 million, for example, that have not received their dollars in New York State. We are working with the States now to see to it that those dollars get out and have been assured that all those dollars will be out,

expanding treatment, by April 2nd. And I will be glad to report to the Commission when we receive the information that that has occurred.

One of the other initiatives that I think is really important is our categorical grants or discretionary grant program. This discretionary grant program will address the needs of HIV-positive drug users through three kinds of programs that we have. I think one of the most important programs, of course, is the Target Cities Grant Program. We will fund treatment improvement--that is, that is my office responsibility primarily is to improve treatment in drug treatment programs and not to expand drug treatment programs. If per chance the improvement of treatment and making treatment more efficacious will result as a fallout in expansion of drug treatment, so be it. But that's not the role of the office. The office is set up only to improve drug treatment. I'd like to make that very clear from the outset.

So one program that we have in our categorical grant program or discretionary grant program is the Target Cities Grant Program, where out of the 50 cities that have a population of 350,000, we will fund 8 of those cities on a

competitive basis that will apply through the States. Only one city can quality from each State. Some States have more than 350 cities. Only 50 cities are eligible to apply, and only 28 States have cities over 350,000, and some of those States have two cities. So we will fund one-third of those cities, about nine of those cities with grants. We have $28 million to do that, and we will fund them for three years to improve their already existing drug treatment programs.

Now, what will some of the Target Cities dollars do? Hopefully, programs that do not have a central referral unit--that is to say, a city like New York City that doesn't have a central referral unit--while we do not know the demand for treatment--we often talk about treatment on demand, but what is the demand in any given city is always a guesstimate. I would hate to take the taxpayers' dollars and put it into a city and build up a magnificent and grandiose treatment system and have no takers, or have only one-third of the capability utilized. I think that would be a waste.

I think that what we need is a better system. And doing so, and putting that philosophy out there, I think what we need are central referral units that are in constant communication with every drug treatment program in that town.

I have done it myself from my office in New York City. I would call the programs on a weekly basis and find out just how many vacancies there were, what kind of treatment was being offered in those treatment programs, and have that information available. As a matter of fact, for six months I supplied that information, gratis, for no cost to the City of New York, to the Commissioner of the City of New York, and to the Mayor's office. So I know it can be done, and it can be done effectively with electronics a lot better than I did it from my office person-to-person calling drug treatment program administrators and providers. And then we would know, perhaps, what is available. That's what we need to know first off.

Secondly, we would have that central referral unit set up so an addict could call that central referral unit any time of day or night and find out where a treatment vacancy existed and to take advantage of that particular vacancy. It could be in his neighborhood or in her neighborhood or a little bit outside of their neighborhood, but whatever was available. And I think we would find that we would have not the number of takers that we think we would have for those treatment slots. That is my prediction.

However, I feel that until we use up the available treatment slots in our Nation, and particularly in our larger cities, that we should not be establishing more treatment slots that will go wasted. For example, in New York City, there are 400 treatment slots today, any time of the week, for intravenous drug users and opiate addicts.

The next discretionary grant program that I think will help to address the HIV-positive drug users or those that potentially will become infected with HIV is the Critical Populations Grant Program. The critical populations are, of course, the minorities--that is, the African Americans, the Hispanic mosaic, Native Americans. We are going to focus on women of childbearing age; prisoners, people within the prison system; we are going to focus on people in public housing units; we are also going to focus on schools, for example. For schools, one of the 1988 Drug Abuse Act mandates was to look at the educational system and particularly high schools and junior high schools, and help teachers be able to find just where to refer people who might be using drugs. That kind of service does not exist, and that is another focus that we have.

We plan a criminal justice system initiative that

will not only focus on people already in prison where we will set up drug treatment programs, but to have people when they are adjudicated, and they might have a substance abuse problem, diverted from the criminal justice system into drug treatment programs. I am very hot on that issue. I think that what we have are people into the criminal justice system, right out again, right back on drugs, right back into the criminal justice system and out again, so it is a vicious kind of cycle.

We also need to have people who will monitor those persons who are diverted to the treatment system from the criminal justice system. We don't have the personnel in drug treatment programs to take care of that problem. We need trained people. We need marshals to take care of that problem, to make sure that that individual stays in drug treatment. We need correspondence that flows steadily from the criminal justice system to the drug treatment program and back from the drug treatment program to the CJS, telling them the status of that individual. And in case that individual absconds from treatment, that individual then would be put back into the criminal justice system.

We also are looking at creating a relationship

between social service agencies and cities where people are on public assistance, and one of the mandates in New York City for people who are using drugs who are on public assistance is that they must be in a drug treatment program. That has not been followed up on. Drug treatment programs do not communicate with the social service system. So we intend to try to tighten up that system.

The three programs, then, are the Target Cities Grant Program, the Critical Populations Grant Program that will target those critical populations, and the Criminal Justice System Grant Program. Hopefully, when those are up and funded--and some of the announcements are going out today, will be on the street tomorrow--I think we may make an impact.

We also have one other area, and that is disaster grant dollars, where, when there is an area that has been declared a disaster area by the President, we have about $2 million to go in there and help them re-establish their alcohol, drug abuse and mental health systems. I think that is important.

Another way we intend to improve drug treatment is through conferences around the Nation. We have a 5 percent

set-aside from our block grant dollars to do technical assistance to States, and we plan to use those dollars to set up conferences and to TA States that will request that kind of service.

I think that if my office accomplishes just half of these things this year, we will have done a tremendous job to help bring about some changes within the system.

One other thing I'd like to mention that is a mission of the Office for Treatment Improvement is the linking of public health services to drug abuse services. That does not take place.

The other thing is mainstreaming of alcohol, drug abuse and mental health problems in the classical public health system arena. I heard Dr. Rogers say something that was close to my heart when he said that the only disease that he knows that is a fatal disease where people have to be on a waiting list and so forth is drug abuse treatment. And he is right. Our hospitals don't have drug abuse treatment as they ought to. If they would get involved in treating drug abuse like we treat every other chronic disease, perhaps the need to say we need treatment on demand and so forth would not be there. And one of the missions of my office is to bring

those institutions and those classical health care providers into contact with drug treatment programs and make them a part of those programs, drug treatment programs, for example, that do not have good primary health care, to establish good primary health care in drug treatment programs; those primary health care programs that are already out there that do not have drug treatment, establish drug treatment within those primary health care programs.

I am working with the National Medical Association, the American Medical Association, the American Society of Addiction Medicine, and plan to have a conference in 1991 of those three groups, sponsored by those three groups, my office, the Office of Substance Abuse Prevention, the National Institute of Drug Abuse, and certainly the Office of the Secretary, and bring them all together to bring to start, hopefully, to have mainstreaming of alcohol, drug abuse and mental health problems.

I think if we do that during my tenure, I will have accomplished a great deal.

So with that, I am open for questions, and hopefully you won't ask me any of those ONDCP questions, the Office of National Drug Control Policy questions, because I don't know

whether I'll be able to answer them or not.

CHAIRMAN OSBORN: Thank you very much.

Dr. Konigsberg?

COMMISSIONER KONIGSBERG: Thank you.

Dr. Primm, I think you made the comment that there needed to be a greater link between the drug abuse system and the public health system. I can recall very early in my public health career--Georgia, as a matter of fact--where the systems were together within the same system. Whether they still are or not, I'm not really sure. But over the years, there has been a widening gap between the mental health and public health systems and between drug abuse and substance abuse from public health and in some cases from substance abuse and drug abuse from the mental health system. It gets rather confusing for many of us, and yet the link with AIDS and HIV is so clear.

Do you have any specific suggestions on how we might link the systems a little bit better?

DR. PRIMM: First of all, I think they are linked now, but in a very loose fashion. When we have individuals in drug treatment programs that happen to come down with HIV disease, they quickly go through our tertiary health care

system, which is the hospital. So there is a link. I'd like to strengthen that link. I'd like to see drug treatment people giving lectures in hospitals, et cetera, in exchange for education, to get out and teach hospital personnel that drug abusers do not have horns and do not have tails and will not bite you if they are treated like human beings, very much like is done within the health care delivery system in The Netherlands; they will embrace that system. We have to make our health care system more attractive to those individuals who have gotten short shrift within our established conventional health care units. And I think we can do that. I think there is a willingness to do that around this Nation because of HIV infection now, and I think it is a window of opportunity for us to insist that this happens.

I think if we get the American Medical Association, the national medical association, and every other professional society associated with medicine to back this kind of thrust, that it will happen.

COMMISSIONER KONIGSBERG: Dr. Primm, I agree with what you said, but I think I was also looking at the link not just with the public health care system but with the public health system and particularly important with prevention,

more specifically with sexually transmitted disease activities and with AIDS activities.

Now, I know there is a lot of that interaction going on, but one of my more frustrating problems when I was still in Florida at the local level, going back two and three and four years ago, was the difficulty of us in the public health system getting the substance abuse people, particularly private, where there was very little control from a State perspective, to really understand the importance of this epidemic and why they needed to work with us. I think there have got to be much stronger links because I can tell you from the State perspective now, it is just as fragmented as it can be, and it is something we are going to have to address with a comprehensive strategy. Now, that does not mean that somebody has got to merge agencies or go through these horrible bureaucratic and turf-guarding hoops, but something where there are incentives all up and down the line, positive, negative or whatever, to get these elements together, because I don't think it is really happening effectively in many areas.

DR. PRIMM: The bottom line, I think, Dr. Konigsberg, is education of both the systems. During the 1980s, we

lost tremendously--the National Conference for Drug Abuse Workers, for example, you mentioned that they did not have the wherewithal to understand the inextricable kind of relationship between HIV infection, STDs, and of course, drug use. We have lost those educational conferences. We need to re-establish those conferences. My office intends to do that, not only among drug treatment workers, but the sponsors from conferences jointly sponsored by classical health care workers. Both groups need it, then to try to bring them together. And I know it would be a utopian act to do so, but you've got to be a dreamer, and I got where I am now in the Office of OTI by dreaming. So of course I think we can bring it about that way. It is just that serious.

I think the other thing is that many States have tried to decree that HIV infection is a sexually-transmitted disease and is reportable, and we have had such a lobby against that. I say that it is a sexually-transmitted disease wherever I go, despite the fact that many people are against saying that. It is transmitted sexually--maybe not as frequently as it is by HIV disease now, at this juncture, but I think that has been a contributory factor among drug users just as much as the sharing of narcotic paraphernalia.

So I think we need to look at that, and maybe this particular Commission can certainly recommend that.

CHAIRMAN OSBORN: Don Goldman, and then Eunice.

COMMISSIONER GOLDMAN: Thank you, Dr. Primm. It is really an honor and a pleasure to have you here.

The Nation as a whole and all of us who have been involved in issues involving AIDS and HIV infection were so impressed with the Commission report that you were such an important part of. I want to express my thanks to you for being part of that process and producing such a wonderful product.

DR. PRIMM: Thank you, Dr. Goldman.

COMMISSIONER GOLDMAN: I was wondering--and I am asking you a question really I guess more in your capacity as a former member of that Commission rather than in your current capacity--I was wondering whether there is anything in your experiences in the almost two years since you issued that report that would cause you to question the recommendation of that Commission which says that in the near term, the National Institute of Drug Abuse in conjunction with State agencies, local drug abuse officials and representatives of drug treatment programs should develop a plan for increasing

the capacity of the drug treatment system so that the goal of treatment on demand can be met.

DR. PRIMM: Let me respond by saying that has partially been done in two ways. I just spoke to you about the increase in terms of the funds available to States through the block grant mechanism to increase the drug treatment capacity. There has been a 160 percent increase since 1987.

There are 329,000 treatment slots available in the United States. The waiting list program, which put out $75 million and another $25 million, has increased those slots--supposedly, it was destined to increase those slots--by 19,000 more.

When we talk about treatment on demand, you heard me just say that in the city in this Nation that has the highest number of drug abusers, which is New York City, that there are presently, on a daily basis--and I don't have data from my program in New York that I could give you today--but between 250 and 500 available slots on a daily basis for heroin users--not cocaine users--I am talking about heroin users--not inpatient drug treatment slots, but these are outpatient methadone maintenance drug treatment slots.

So when we start to talk about treatment on demand, we need to look at the demand for treatment on the part of the addicts themselves. We need to see what we have in our system that we do not have. This is the first program that I have ever seen for treating any disease that we don't have a handle on either end of the problem.

I hope some of the dollars in my office will be able to do that. I am working with NIDA. I am working with the Office of Substance Abuse Prevention. I am working with the Health Resources Administration also to establish drug treatment not only in other institutions that classically did not have drug treatment, but to establish drug treatment in community health centers, for example. All of that is part of what I feel answers just the think that you read in our report.

CHAIRMAN OSBORN: Dr. Diaz?

DR. PRIMM: Dr. Diaz--how are you, Eunice? It is so good to see you.

COMMISSIONER DIAZ: Hi. It is good to see you again.

I think you know this, but as a Latina, let me express to you that we really have a concern for what is

happening with women who are HIV-infected, and we know that the majority of those women are being infected through their own IVDU, their own intravenous drug use. Many times, I think we forget that in the establishment and funding of treatment programs that specifically address the needs of the addicted woman of color. I just wanted to remind you of that. I think you and I have had previous conversations in your previous position about the tremendous needs that really are not focused on when we develop treatment programs in this country, focusing on specific needs of addicted women.

I also wanted to ask you if any of the programs you have described today out of your office, Beny, really focus on where HIV incidence is highest. In other words, when you talk about giving funding to eight cities of potentially 50 cities that are eligible, is some priority given to cities that have a high sero prevalence?

DR. PRIMM: Absolutely.

COMMISSIONER DIAZ: Okay. You didn't say that, and I just assumed it.

DR. PRIMM: Absolutely.

COMMISSIONER DIAZ: And my final comment is that I really think that the last statement that you made regarding

the initiatives out of HRSA and NIDA and your office for inclusion of drug treatment availability within primary care centers and community health centers is very laudable. I hope that this will be evaluated shortly so we can get more dollars into that. As you know, there were some excellent proposals that did not get funded this time, and I know that some of those communities are really very, very hopeful that introduction of those moneys via community health center and the primary care system will provide an answer particularly for underserved communities that have little access to care.

My final suggestion to you was going to be something I suggested to Dr. Shuster of NIDA before, and it has not been addressed. But from the Hispanic community, we would like to propose that one of those conferences which your office might give priority to is a conference on Hispanic HIV and drug use. It is desperately needed.

In your previous position at the Addiction Center in New York, you began some of the work for that in one of the conferences I participated in, and I think that right now we feel that there are enough of us working in those communities with knowledge of what is happening both in terms of HIV and us as Latinos to be able to present to not only this

group but your office some strategies and specific experience that comes from our knowledge of working in those communities.

DR. PRIMM: Let me respond to that, Dr. Diaz, by saying that the 1988 Drug Abuse Act, Public Law 100-690, established a number of critical populations on which one had to concentrate by Congressional act. One of those critical populations was women and children.

My office was not, of course, established at that time. The Office of Substance Abuse Prevention was. And they now have that primary initiative going even though my office also is to focus on that initiative. But since OSAP has gotten out announcements relative to women and children both in treatment and in prevention and education efforts, we are sort of caboosing on what they are doing so that we don't confuse the public that there are two places that these announcements are coming from.

In that regard, my associate director of the Office for Treatment Improvement is one of the leading experts in this Nation on women and children born to addicted mothers. That is Dr. Loretta Finnigan. She has been in my office now for about a month, month and a half. Dr. Finnigan will have a dual appointment in the Alcohol, Drug Abuse and Mental

Health Administration. She will have an appointment in my office as the Associate Director of the Office for Treatment Improvement and an appointment in the Office of Substance Abuse Prevention as their medical advisor in that office.So I am happy to announce that there is a thrust for women and children.

We also plan for the Hispanic mosaic in this Nation, and African Americans and Native Americans. We have already received some requests from Native Americans and the Hispanic mosaic to have such a conference, focusing on problems specific to those critical populations. We have also received a request from the Native American population to focus on those individuals.

We plan to do a whole TV kind of series. Recently I did a series like this, where they came to my office; I talked over slides; it was televised in my office and then taken back to a central station out in San Diego and beamed to 33 different treatment programs, social service programs throughout our Nation.

Then I came on the next hour and answered questions from each one of those programs around the Nation that had questions. They had assembled audiences through audiovisual,

taping--I don't know how that system works--but anyway, it was extremely effective. We plan to do some of those kinds of things because we don't have so many people that can go around the country and lecture here, there and the other place, and then have one or two general conferences, regionally based, to hit both the Hispanic mosaic population, African Americans, Native Americans, Asians. I am going to send some people out to Guam and other Territories of our Nation because they get short shrift also.

I thank you for that suggestion.

CHAIRMAN OSBORN: A last quick comment or question from Diane Ahrens.

COMMISSIONER AHRENS: Thank you.

First of all, you mentioned that you were targeting money to cities. Were you using cities in a sense of local governments, since most of the areas of the country, it is counties that provide the treatment for addiction? Am I misunderstanding?

DR. PRIMM: No, ma'am. What will happen is all of our moneys because of Congressional mandate have to be spent under an authorization called 509(g). That is mandated from--I talk like a bureaucrat, and I know my friends are wondering

what the hell happened to Beny Primm--

CHAIRMAN OSBORN: I was just going to say that.

[Laughter.]

DR. PRIMM: We can only spend our money through States. In other words, the grants will come to the States and then to us. We can't go directly to the cities. With the new federalism and this Congressional mandate, the contract has to be done with the State.

COMMISSIONER AHRENS: Okay. I think I understand that.

CHAIRMAN OSBORN: A last shot from Don DesJarlais and then we'll break.

COMMISSIONER DESJARLAIS: Just one quick comment about treatment on demand and capacity and such. In a normal general medical hospital, operating at capacity is believed to be about having 85 percent of your beds filled so that you still have a little flexibility to deal with emergencies that come up.

Dr. Kleber said that treatment on demand would have required a drug treatment system that basically operated at about 90 percent capacity, again so you had a little flexibility for variations.

The New York situation that you talk about, with 400 open slots, is true. That represents a system that is operating at 99 percent of capacity, of about 40,000 slots. So that by Dr. Kleber's definition of what treatment on demand would be, rather than 400 open treatment slots in the New York system on any day, there really should be 10 percent, or about 4,000, slots to have the flexibility of being able to send people to a program that was convenient for them, that matched their needs, so that while there certainly are 400 open slots in the New York system on any given day, that does not mean that the system can provide treatment on demand given either Dr. Kleber's definition of treatment on demand or the normal medical system of treatment on demand, which would have 15 percent open slots.

DR. PRIMM: Don, let me say to you that I have here data that will account for 4,000 more treatment slots in New York State. About 3,000 of those slots would be in New York City that would be covered by the waiting list dollars that have been allocated to New York City.

COMMISSIONER DESJARLAIS: Yes, okay. That was actually just a point of information. My real question is your office is for treatment improvement. Many of us are

worried about just maintaining the quality of the treatment programs we've got now. HIV disease is causing tremendous emotional difficulties for staff as they see their good patients dying, as they see children infected. To what extent do you plan on addressing the staff burnout, emotional difficulties, that are coming with the HIV infection as part of an OTI initiative?

DR. PRIMM: Okay. First, Don, I think, even expanding on your question to me, is that drug treatment staffs are underpaid, overworked--all of the things that create the kind of stressful situations that speed up burnout. I came from that system, and you know that. One of the things that I have said is that States can use dollars in the Target Cities initiative, in the Critical Populations initiative, and even in the prison system initiative, to raise salaries, to have EAPs, to have an Employee Assistance PRogram created. They can have a psychiatrist or psychologist on staff to take care of staff problems. We need ongoing intramural education for drug treatment programs, and I am willing to fund a single State agency to carry out those programs.

And then, remember, 5 percent of the ADMS block

grant can be used for technical assistance to take care of just those problems and, on request by the States, to have an ongoing training program, conferences, et cetera. So some of the States are aware of that and are applying for those dollars.

The other thing, in States like Minnesota--and I think your question is an excellent one, and let me add to your question if I may, Mrs. Ahrens--let's say you have a single State agency that is biased relative to certain treatment programs within that State, and you receive an announcement at the State level, and it just does not filter down to drug treatment program providers, who then cannot apply for those dollars that are available throughout the State. Okay, that happens. That happens in Puerto Rico, that happens in the Virgin Islands, that happens in the State of Florida, et cetera. These are specific complaints that I have had directly to me and to my office as I move around the country.

What we intend to do is to mail those announcements directly to treatment programs so that the treatment program will be aware of what is available and the mechanisms to apply.

The other thing is that we can offer technical assistance to specific drug treatment programs that may be applying for some of these grants. So many programs out there do not have good writers, for example; many minority programs don't have the kind of expertise that an academic-based institution has. So we intend to match some of this talent with some of those programs so that those programs can take advantage of some of the offerings that we have under OTI.

CHAIRMAN OSBORN: Dr. Primm, thank you so much. I think we all feel awfully good about having somebody of your distinction and the physician you are, and we are really very happy that you were able to join us today.

DR. PRIMM: Thank you, Dr. Osborn.

CHAIRMAN OSBORN: I think now we should take a belated break. Our hosts have been most kind in again letting us meet at the Pan American Health Organization. The coffee is available on the floor below, and they would appreciate it if it stayed on the floor below.

So we'll reconvene in 15 minutes.

[Recess.]

CHAIRMAN OSBORN: We will catch ourselves up with

our schedules and take advantage of the unfortunate fact that the people from Housing and Urban Development who were going to join us this afternoon cannot. We have made a slight revision in the way we will proceed now, with Don DesJarlais' graceful concurrence.

We are very grateful to Drs. Brown and Haverkos for having been patient with us this morning, and we'd like to take full advantage of their expertise. So, for roughly the next 45-50 minutes, we will hear from them and get a chance to ask them questions.

When we have done that, we'll take our lunch break, and then when we reconvene, Don DesJarlais will talk, and we'll have a chance to interact with him as witness for a while as well as a fellow Commissioner. That way, we do the least additional violence to the schedules of those who have been kind enough to come and join us.

So with those introductory comments, Dr. Haverkos is first. Dr. Harry Haverkos is Acting Director of the Division of Clinical Research at National Institute on Drug Abuse, and an old colleague.

Welcome.

STATEMENT OF DR. HARRY HAVERKOS, ACTING DIRECTOR, DIVISION OF CLINICAL RESEARCH, NATIONAL INSTITUTE ON DRUG ABUSE

DR. HAVERKOS: Thank you.

Madam Chairwoman and members of the Commission, I am Harry Haverkos, Acting Associate Director for AIDS and Acting Director, Division of Clinical Research at the National Institute on Drug Abuse.

I am representing Dr. Charles Shuster, the Director of NIDA, who sends his regrets. I am accompanied today by Dr. Barry Brown, Chief of the Community Research Branch at NIDA.

We are pleased to have this opportunity to share with you information on the activities of the National AIDS Demonstration Research, NADR, or NADR project, the most ambitious research and demonstration effort ever supported by NIDA.

Initiated in the fall of 1987 with six grants and five contracts, and expanded one year later to 54 cities nationwide, the NADR project is now in full operation. Our programs have made contact with more than 80,000 intravenous drug abusers not currently in treatment, sexual partners of

intravenous drug abusers, prostitutes, and adolescent runaways.

Twenty-two thousand of these individuals have been recruited into some aspect of a behavior change program.

Our remarks today will focus on five areas. I would like to trace briefly the development of the NADR project and place it into some historical context as well as into the context of the AIDS epidemic. I will also mention some of the research and demonstration programs that are flowing from and progressing in tandem with the findings from the NADR project.

Following this, Dr. Brown will talk about the structure and approach of the project, stressing its unique features. Some findings to date as reported from the 63 program sites to NIDA's National Data Coordination and Evaluation Center will be discussed. The presentation will conclude with some thoughts about the continuation of the project once the initial three-year demonstration period has ended.

In the early 1980s, America was awakened to what many believe is the most significant public health threat of the century: Acquired Immune Deficiency Syndrome. Early in

the epidemic, we were aware that the threat of AIDS was not limited to certain high-risk groups, namely gay men, but rather that HIV infection was a consequence of high-risk behaviors. Intravenous drug abuse was one of those behaviors that placed individuals at risk for contracting and transmitting the virus.

The complexity of the interrelation between AIDS and drug abuse became increasingly apparent over time. HIV transmission from i.v. drug users to their sexual partners currently accounts for over half the heterosexual AIDS cases reported by the CDC. Of AIDS cases in children born to mothers at high risk for HIV infection, more than 70 percent are related to intravenous drug abusers.

More recently, we have begun to appreciate the connection between HIV transmission and the use of crack cocaine and other forms of non-intravenous drug abuse. Although crack is smoked rather than injected, it is frequently connected with increased sexual activity, both because of cocaine's stimulant properties and because sex is traded for the drug, or money to purchase them.

The needs for drug abuse treatment have become clear over time, but there have not been enough drug treatment

slots available to meet those needs. In addition, many drug abusers are unwilling to enter treatment, and outreach to this group was clearly indicated.

NIDA's response to the epidemic was pragmatic and straightforward. We realized first of all that the exponential growth of the recognized need for treatment could not be met by an incremental growth in treatment programs, at least initially. We needed new approaches that were based on successes in the past. We were aware that, lacking resources to increase drug treatment slots, we could not wait for i.v. drug users to come to us. We had to go to them. That meant taking our service, knowledge and research programs to the streets and to institutions with which this population interacts on a regular basis.

These were to become the fundamental premises of the NADR project. In developing the project, we wished furthermore to create a program that was so structured to take full advantage of NIDA's new emphasis on technology transfer.

In other words, we were committed from the start to communicating our findings to the treatment community in order to improve service delivery.

The NADR demonstration research project already has yielded important results. They have shown that many intravenous drug abusers have never been in treatment, and many engage in high-risk needle sharing and sexual behaviors. Many intravenous drug abusers contacted by the outreach workers were found to be willing to reduce or eliminate high-risk behaviors, and many were willing to consider drug abuse treatment. However, treatment was not always available, and that which was available was often inadequate.

The outreach studies also showed that cocaine injection is a serious concern, and that injection-linked HIV infection is not limited to persons who abuse heroin or other opiates. In fact, higher HIV sero-prevalence rates are found for cocaine injectors compared to opiate injectors in several United States cities. The need for improved treatment for cocaine addiction is clear.

NIDA as a research institute is committed to conducting studies in these important areas where the outreach program has identified gaps in our knowledge. This research will concentrate on developing new and improved methods for treating drug abuse, with a particular focus on the treatment of cocaine abuse. Behavioral, psychosocial,

pharmacologic studies are either being planned or are underway. Some potential programs that can be mentioned at this time include demonstration projections, some underway, more planned, to find more effective treatments for drug abusing pregnant women and their infants; a medications development program that is searching for pharmacologic agents that can help in treatment cocaine and other drug addictions; treatment research units that have been established to test various interventions under controlled conditions; linkage and money transfer to Health Resources Services Administration to try to link and explore ways to merge the primary care system with the drug abuse treatment system.

Another initiative undertaken with the Government of the District of Columbia would provide outpatient treatment and residential treatment within a research setting for D.C. residents addicted to drugs.

I would like now to introduce Dr. Brown, who will continue this presentation.

STATEMENT OF DR. BARRY BROWN, CHIEF, COMMUNITY RESEARCH BRANCH, NATIONAL INSTITUTE ON DRUG ABUSE

DR. BROWN: Thanks very much, Harry.

As Dr. Haverkos indicates, the program I am going to describe, the Demonstration Outreach Program, got started in 1987 initially with the six grants and five contracts.

The populations of concern at that time and that continue to be of concern in terms of this program are four. I think it is fair to say that certainly initially, because of the urgency of the situation with these groups, particular emphasis was placed on the first two--that is, intravenous drug users, meaning here out-of-treatment intravenous drug users, the sexual partners of intravenous drug users, as well as prostitutes who, of course, are themselves frequently intravenous drug users, but sometimes fall between the cracks, if you will, in terms of services and concern for issues regarding that population, as well as adolescent runaways which has been a population of increasing interest and concern within NIDA in terms of the fact that again we have youngsters who are frequently engaged in drug use, albeit non-intravenous drug use, although certainly disinhibiting drugs on the one hand, and on the other are, of

course, living in situations in which they are most frequently trading sex for their very existence and obviously thereby significantly at risk for AIDS.

As the program has grown now to the 54 cities that Harry indicates are currently covered by NADR programs as they come to be called--a rather unfortunate acronym, I think--in any event, as you can see, the programs are concentrated in the Northeast. They did attempt to follow the problem, as it were, in terms both of intravenous drug use and prevalence of AIDS. Having said that, they have really, obviously, become spread throughout at least a significant portion of the country and certainly in some lower-incidence areas throughout the country.

I might indicate that the program, just in terms of its very general structure, if you will, there are 41 projects total that are currently operational. Twenty-nine of these are comprehensive community grants, meaning that they are intended to serve, again, at least the two populations that I was indicating as being of paramount concern--that is, intravenous drug users out of treatment, and the sexual partners of intravenous drug users. And they use a variety of strategies, as I will get into, to reach and to

attempt to intervene with those groups in terms of effecting behavior change and research designs intended obviously to understand the efficacy of those intervention strategies.

We also have 12 contracts which are somewhat more targeted and really deal with particular populations in a given contract city, if you will; they will look at intravenous drug users that are reached through the criminal justice system, as one example. They will attempt to reach sexual partners through housing authority programs. But there will be an effort to reach particular populations, typically in particular settings, and again to assess the efficacy of strategies designed to accomplish that.

I wanted to just briefly walk through the general design of the studies that are in force and also lay out the general program.

Initially, contact is made through outreach workers, indigenous workers, typically, individuals who know the community, know the individuals who they are attempting to reach, aspects of some of the same background, which is to say that frequently we are using ex-addicts to reach the intravenous drug using community. Contacts in terms of intravenous drug users are typically made on the street, that

is, in copping areas, areas where drugs are bought and sold, are made in the criminal justice system, in lockup settings, in probation. Outreach contacts may be made in hospital emergency rooms as well--areas, obviously, in which the out-of-treatment intravenous drug user is more likely to be located by virtue of his or her concerns or problems.

The sexual partners may be contacted on a much wider range, as I was indicating--housing authority sites, beauty parlors and laundrettes in a variety of communities; we will go through prenatal programs where individuals are taking advantage of prenatal programs; we will go through ob-gyn programs; we will attempt to work through the intravenous drug user located in drug abuse treatment--unfortunately, that has not been a terribly effective strategy. But at any rate, we'll attempt to reach women at risk where they can be contacted and where they are most likely to be found.

Individuals will be referred to interview--the AIDS initial assessment, which shows in the third block. The interview is a part of the research protocol and designed to allow us to understand the behaviors and characteristics of these populations. The AIDS initial assessment is a structured interview schedule--that is, it is invariant in terms

of its format. All individuals have been trained by the same trainers, so we think that we will get relatively little bias at least in terms of the measure, and we will be collecting--and as you'll see, I think we have collected--a large amount of information in terms of the characteristics of the populations.

That particular interview schedule also forms a baseline in terms of understanding the efficacy of the intervention that is then employed. Again, this gives behaviors of individuals in regard to sexual practices, in regard to drug and needle use before any kind of intervention is attempted with the groups.

A locator form is collected at the same point as the AIDS initial assessment, and again, a locator form is simply to allow us to gather information that will enable us to find the individuals some six months after the intervention so that we can assess the efficacy of that intervention.

All individuals are offered the opportunity for HIV testing, including pre- and post-test counseling, in conjunction with the HIV test.

Again, in terms of the way in which the studies have evolved, individuals will then be randomly assigned to

either a standard intervention, which is the typical CDC intervention combining some counseling with didactics, or to an enhanced or innovative intervention in which the investigator will be testing for its efficacy against the standard or usual kind of intervention.

Six months later, all of the subjects who can be located will be given an AIDS follow-up assessment designed to understand the extent to which there has or has not been changes in individuals' behaviors.

COMMISSIONER DALTON: Excuse me. Before you leave that slide, I can't tell whether it's only those people who take advantage of the opportunity for HIV testing who then go on to one of the two interventions, or whether it is everyone.

DR. BROWN: It is everyone. All individuals are offered the opportunity for HIV testing, but it is not required in order to go on to the intervention. And I should indicate--again, as Harry did indicate--that we have actually reached, or the projects have actually reached, some 80,000 individuals in terms of some form of outreach, that is, some form of provision of educational materials and expressions of concern and some level of counseling with regard to behaviors on the street.

This really relates to the roughly 20,000 folks who have now gone through the research portion, the portion designed to understand the efficacy of interventions.

At this juncture I have to hasten to add that in the earliest programs, it really was a pre-post kind of study, but at this juncture there is a randomization into the two kinds of programs.

I just want to walk very briefly--all too briefly, I'm afraid--through the interventions that are employed. In general there are three types--the first three bullets that appear there. I am talking now--I am sorry--about the innovative interventions.

On the one hand, counseling strategies will be employed embracing the usual individual and group, as well as couples counseling where IVDUs and their sexual partners can be engaged in the same group.

The effort obviously is not unlike that which goes on in any kind of counseling procedure, an effort to understand resistances to behavior change, to support efforts to make behavioral change, and to support any changes that are made in individuals' behavior through time.

Frequently, it will be combined with a skills

training or, if you will, skills training will be combined with the counseling strategies, behavioral skills training, which will involve not only an understanding of how to make use of materials that will allow individuals to be less at risk for HIV infection, but will also involve things like learning negotiation skills in terms of sexual partners of intravenous drug users in particular, such that women in particular, although obviously not exclusively, can be allowed to understand strategies that they can employ in terms of getting their partner to make use of condoms, to use protective sex, in order to protect themselves and of course others from the threat of infection.

In some of our programs, there is an effort in terms of cognitive skills building so that individuals script out responses to dangerous situations, situations in which people ask to share their needles; what is a response with which you would be comfortable and could still reject this behavior since it places you at risk. They script out and practice the behaviors and again learn new techniques, if you will, for adopting risk-reducing behaviors.

Two other elements that I should mention that are not uncommonly associated with both the people using counsel-

ing strategies or programs using counseling strategies and programs using skills training.

One is a case management approach. Many make use of case management in addition to either counseling or skills training, that is, the effort to locate resources for individuals in the community that again can help them with their overall lifestyle, which obviously then plays into a greater capacity to reduce risk.

In addition, some number of programs will make use of a kind of increasing sense of vulnerability among clients or subjects. Dr. Primm was indicating that these are folks who are putting a needle in their arms on a daily basis; they are quite literally running a risk of death on a daily basis. Many programs feel that it is useful to aid individuals, if you will, to have a greater sense of anxiety about the risk-taking behavior specific to HIV infection in order then to make them accessible to counseling or behavior skills training, which obviously must then be employed to reduce the level of anxiety that has been created but is used as a mechanism to allow individuals to understand risk and to begin to limit that risk in themselves.

Finally, in terms of peer support systems, this is

an effort that is made in a large number of programs where the outreach worker and the interventionist are the same person, and these other programs, the outreach worker is typically referring individuals to others who will provide counseling, others who will provide behavioral skills training. In a number of the programs, the outreach worker and the interventionist, as I say, are the same person, and what they attempt to do is to work with the group, the street corner group or the group particularly encountered in the copping area, in order to make an effort to change norms, to change behaviors, by having an impact on the group norms.

It is really using ethnography in some sense, dropping the element of nonparticipation in terms of the usual ethnographic approach and having the individual who is working with the group very much invested in some of the issues with which the group is dealing and then trying to effect behavioral change.

Finally, virtually all programs make use of some element of didactics, some element of educational practices, some sharing of materials in terms of condoms, in terms of instructions with regard to sterilization practices, or indeed in terms of bleach kits.

It should be stated and it should be understood that again, in virtually all of these efforts, the first interest is getting individuals into drug abuse treatment, which is seen as being the first and the best mechanism for effecting long-term behavior change. As Harry was indicating, there are certainly some number of individuals who will not or cannot take advantage of the treatment program, and many of the strategies that I have been recounting are designed to help those people begin to change their behaviors.

Let me get into a discussion--the research has two aspects, as has been indicated. One is to understand these previously, largely hidden populations, populations about which we knew very little. Actually, Dr. Kleber is one of the very few people who did any study with regard to out-of-treatment heroin users in that instance. At any rate, on the one hand, as I say, the research is targeted to understanding what these populations look like and how they are functioning and on the other to understanding what strategies may be effective in effecting behavioral change in these individuals.

So we now have data, obviously, on over 16,000 intravenous drug users again who are out of treatment at the time they are located. As you can see, they are overwhelming-

ly male, represent overwhelmingly minority ethnic groups, and are young, 53 percent below the age of 34.

Again, some of these charts will simply indicate the level of risk that folk are running. This is in terms of behavior reported over the six months preceding interview. Seventy-five percent of male intravenous drug users report themselves as having rented or borrowed needles; 70 percent of women report themselves as having rented or borrowed needles, all of them placing themselves at risk at least some portion of the time in the six months preceding interview.

In terms of the numbers of persons with whom they share needles, again, more than 80 percent of both males and females share needles with at least one other individual. Virtually two-thirds of the men and 60 percent of the women share with two or more people.

This relates to the extent to which individuals are engaged in any sterilization practices with regard to their needle use, again over the course of the preceding six months. Essentially a little more than 10 percent of both males and females, 11 percent and 12 percent of males and females report themselves as always using new needles and/or sterilized needles and always also not sharing cookers or

cottons or rinse water. The middle category, 17 and 20 percent, represent folk who say they always use new or bleach-cleaned needles, but share cookers or cottons or share common rinse water and consequently can be seen obviously as placing themselves at risk as well. And the remaining percentages do not sterilize their needles, have not been sterilizing their needles over the course of the preceding six months at least some portion of the time.

Obviously, essentially what we have is nearly 90 percent of the group is placing themselves at risk by virtue of their needle use at least prior to the initiation of interventions.

I think this table, if you will, is particularly significant in relationship to the whole effort of outreach. I mean, in some respects one can ask, okay, are we reaching a different population, which it seems to me helps to justify a concern with the conduct of outreach--are we reaching a different population than those folk who come into treatment; are they really out there.

I think in some respects the most significant portions of the table are the numbers that are shown under the two headers at the top--the "n" equals 6,561 and the "n"

equals 9,712. In plainer language what it means is that 41 percent of the people being reached on the street, intravenous drug users being reached on the street, have never been in a formal drug abuse treatment program. That's a lot of folk.

Moreover, if we look down to the third line, in terms of the average length of time injecting drugs, those people nonetheless have been on the streets injecting drugs for more than 11 years on the average--not terribly different, although the numbers are so huge it would certainly be a significant difference from the individuals who have been in drug abuse treatment. But it has a clinical significance, really, of its own. Forty-one percent of people having never been in treatment that are being reached on the street and that have been injecting drugs for 11-plus years. If you look down, you can see that a key difference perhaps between groups comes in the extent to which individuals are invested in heroin use; that individuals are considerably more likely to have entered drug abuse treatment if they were invested in frequent heroin use, whether it is heroin alone or heroin mixed with cocaine in a speedball, but they are significantly more likely to have come into treatment again if invested in heroin.

COMMISSIONER DALTON: I'm sorry--did you control for the availability of programs for different kinds of drug users? That is, if you're talking about cities in which there are programs for heroin users but not for cocaine users, then it is not surprising that the latter group would not--

DR. BROWN: I think that plays a very definite role in it. I mean, I think that in general, we have strategies that are seen as being more efficacious with regard to heroin than with regard to cocaine, and I think that does play a role in people electing treatment on the one hand.

This relates to the sexual practices or the condom use and sexual practices, again, the intravenous drug using population. In some respects, perhaps the chart can be most easily understood in terms of the darkened portion in relationship to the two shaded portions. That is, the light portion in the charts relating to males and females refers to individuals who are not engaging in sexual activity over the course of the preceding six months. It works out to about 20 percent of each group. But you can see that the darkened portion of those people who are practicing sex, the extent to which individuals are never using condoms and never engaged in protected sex, and you can see that the majority of

individuals, regardless of sexual preference, if you will, are engaged in unprotected sex.

As I was indicating, we also are looking, of course, at the sexual partners of intravenous drug users. They constitute a smaller portion of our total, but this represents over 2,000 subjects or over 2,000 clients. Again, they are obviously--although this is hardly the only concern with this population--they are well into their childbearing years in terms of their age. The population is distinctly minority again.

These are female sexual partners of intravenous drug users who are not involved themselves in intravenous drug use. You can again see that significant minorities of the population are engaged in a use of disinhibiting drugs, a significant portion of the time--perhaps most strikingly, of course, over one-fifth of the women who are involved with crack. So again, this is obviously in significant part, at least, a drug using population itself.

In terms of condom use, as you can see, there tends to be somewhat greater reliance on condom use, although again individuals are obviously placing themselves at risk or a very significant portion of the people are placing themselves

at risk continuously in both groups. But if individuals are engaged with multiple partners, they are at least somewhat more likely to minimize their risk of HIV infection. Nevertheless the story obviously is not a good one. Essentially individuals are not taking appropriate risk-reducing kinds of behaviors in relationship to HIV infection.

COMMISSIONER AHRENS: Could I ask a question about the prior slide. One of the things we have learned about the adolescent population where I come from is that they do not consider multiple partners, even though they may have 15 a year, but they only have them one-by-one. So is that reflected at all? I mean, how did you define individual--

DR. BROWN: It really was having sex with more than one person over the course of the preceding six months, essentially.

This gets now to--again, most significantly I think these studies are concerned with understanding the efficacy of strategies. Again, as Harry was indicating and as I have to re-emphasize, projects are largely midstream. Most of the projects are in their second year at this point. What we have shown here are five projects that are in their third year and consequently have generated some useful data in

terms of understanding the efficacy of the approaches that have been used.

I think on balance, with particular regard to some aspects of drug using behavior, the picture is at least a better one--that is, that the--

VICE CHAIRMAN ROGERS: Dr. Brown, excuse me just a moment. I think we are a little concerned about time. You may be telling us more than we need to know about a very important study, but could you plan to summarize fairly shortly?

DR. BROWN: Surely. I apologize.

VICE CHAIRMAN ROGERS: Not at all, no, no. It is most important data.

DR. BROWN: Let me walk through this, then, very quickly. In terms of the frequency of use of intravenous drugs, what you can see is that there is substantial decrease across-the-board, of course, all five cities. This, again, is taking the first testing relative to the second testing six months after the intervention. In terms of borrowing of works, of needles, there is again a fairly dramatic decrease shown by individuals--by a healthy minority of individuals, if you will--in four of the five cities. It is about one-

third in those four cities. Similarly, there is somewhat lesser diminution in terms of renting, but still a very healthy minority of individuals who have effected changes in their behavior.

Bleach use in terms of efforts to sterilize needles--as you can see, both in terms of bleach and in terms of the use of bleach or alcohol--are up. I think it is fair to say dramatically with the exception of San Francisco, which frankly may have been inundated with information about this and may not have had quite as far to go in terms of effecting change.

I think again, because of the importance of getting people invested in long-term efforts to change behaviors, the percent entering treatment are, I think, dramatic. Percentages of people who enter treatment over the course, again, of the preceding six months--that is the preceding six months after the intervention--I should indicate the blanks are cities for which data is not yet available. Houston has very limited treatment capacity, unfortunately, and that I think is at least partially the reason for the figure that is shown there.

There is somewhat lesser change in terms of some

aspects of sexual behaviors, still in terms of at least a couple of the sites. There are fairly dramatic changes in terms of the diminution in number of sexual partners; some dramatic increase in San Francisco in terms of condom use with a single partner.

Let me talk then briefly to two other issues and then I will be at an end.

VICE CHAIRMAN ROGERS: Move along fairly briskly.

DR. BROWN: All right. Just to indicate the four areas that we get into, because an issue obviously becomes--okay, we find out things--what do we do with them, and how do we try to effect any kinds of changes in communities?

One of the things that we have issued, and you have copies of it, is a quarterly newsletter which is send both, of course, to all of our programs, but also to all State agency directors in an effort to encourage, obviously, some change in programming and some activity. We hold annual meetings, and I can make available to you the proceedings from the last annual meetings, which again are very widely shared.

All of the programs are required to put together outreach intervention manuals as a part of the price of

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playing in this game, as it were, and what we intend to do is to make use of the outreach intervention manuals for those programs that are found to have efficacy and share those with the State agency directors and share those indeed as widely as we can with strategies for attempting to allow changes in program.

Finally, we make efforts to make certain that materials are placed in the refereed literature.

I'll stop there.

CHAIRMAN OSBORN: Linda?

COMMISSIONER MASON: Do we have some time?

CHAIRMAN OSBORN: Yes, indeed. That's one reason why we were asking if we could move along.

Thank you very much for your presentation.

Linda, why don't you start off?

COMMISSIONER MASON: Dr. Brown, I want to ask you, in the newsletter you pointed out that most programs provide HIV testing, pre-counseling and post-counseling. What happens to people who are found to be HIV-positive? What sorts of follow-up do you have for them? I noticed a vague reference to other community service referrals. What I'm trying to get at here is I am not sure what people with AIDS

and HIV infection have to gain from participating in these studies. I'm not sure if--I mean, it is really nice to have all this wonderful data, and we need to draw these conclusions, but I wonder how it is being played out in people's lives. Like in the pre-test counseling that people receive, are they told about what could possibly happen to them if they are HIV-positive and where they can go for medical care, and are there support services in place and referrals? Is it really being played out in reality?

It seems that lots of the things you have said here are very detailed and really commendable in terms of what kinds of information you want to gather and what you hope to do with it; I am just really concerned with what is happening to the people who are actually participating in the studies once they find out that they are HIV-positive.

DR. BROWN: Again, here is where I think case management comes into play with individuals who are seropositive. There is an effort typically--and I can't unfortunately pretend that it is across-the-board--but I think it is fair to say that typically in programs there is an effort to provide significant case management services to link individuals up with whatever support groups do exist in the

community, whatever medical services are needed, whatever other kinds of social services can be useful.

COMMISSIONER MASON: I don't know what you mean by that, I'm sorry.

DR. BROWN: I'm sorry. That was my deficiency. Essentially, that as a part of the intervention, if an individual is found to be sero-positive, he or she still becomes a part of the effort at intervention. As a part of that effort at intervention, a worker would work with the individuals in terms of locating resources in the community where support systems or support groups would exist--

COMMISSIONER MASON: Medical care, primary care?

DR. BROWN: Yes, attempt to access medical care, hospice care, whatever.

COMMISSIONER MASON: How often does that really work?

DR. BROWN: I think it is fair to say that it is really occurring in these programs. In the 41 projects that I have indicated, there is an active effort to find services, to find resources for individuals that are located who are sero-positive.

COMMISSIONER MASON: Well, I need to tell you that

I have friends in cities that have been involved in the demonstration projects, and what they report to me is that it is really not like that, that unfortunately, what has happened in many cases is once people are found to be sero-positive, there is not anything to do with them, and nobody told them beforehand that there wasn't going to be.

DR. BROWN: I really would like to know which--I don't mean you have to tell me here--but I really would like to know what locations, because I would like to follow up on that.

COMMISSIONER MASON: Yes, I would like for you to. Thank you.

CHAIRMAN OSBORN: Don?

COMMISSIONER DESJARLAIS: I wanted to speak directly to that. Obviously, what to do with sero-positives is going to be a much bigger problem in the cities where there are many more sero-positives. And being affiliated with a couple of those demonstration projects, you get almost into a Catch-22 situation of many of the support groups for HIV-positive people in New York require that drug abusers be in formal drug abuse treatment to participate in those support group activities. Then we get back to the earlier

discussion this morning of not having formal drug abuse treatment available for those sero-positive people so that they can get assistance for the drug abuse problem and also qualify for support group assistance for their HIV condition.

CHAIRMAN OSBORN: Eunice, you also had a comment.

COMMISSIONER DIAZ: Are there any clinical trial opportunities for people who are enrolled in the programs that you have described? Are they at least referred to the clinical trials in the area?

And the other question that I have is is there really a future for the outreach programs you have described in terms of funding beyond the demonstration periods. Many of our communities that are providing some of the data that you have shown here are concerned because funding periods are coming to an end and the cadre of workers and intervention, which by your own admission and others' evaluation, is really doing the job for a number of people, particularly on the streets in highly-impacted cities, that these particular programs are running out of funding very soon.

My final concern is that there seems to be--and please correct me--a lack of minority researchers both at NIDA and within the kinds of research programs that you fund

around the country, and because--again, by your own numbers and charts there--this is a problem so heavily impacting Afro American and also Hispanic communities, what kinds of steps is NIDA taking to either increase the research capability for being able to impact what is actually going on, other than a collection mechanism and being able to tell us, you know, these are the kinds of data that the composite of programs is showing. What are you specifically doing to target where the problem is the most acute in relationship to what we are concerned about here as an AIDS Commission?

DR. BROWN: Several things. There is a dearth of minority investigators. I think that really does constitute a problem. There is--and Harry may be able to speak to this better than I--the Institute is engaged in some efforts in terms of encouraging investigators from minority ethnic groups; has scheduled and is continuing to schedule workshops designed to encourage investigators to come in and to deal with some of the issues around the preparation of research grants.

In terms of the larger community, I think there is no question but that with regard to the sensitivity of the issues with which we are dealing, if behooves us to make

certain that there is minority input in terms of understanding the issues and being able to investigate the issues intelligently.

I can only say that the effort is continuing. We are about to let a contract that is designed to again look at differing strategies that are specifically tied to minority ethnic communities with an effort to building models that on the one hand can potentially be of use in those communities and on the other, that we hope in this process actually will engage the attention of minority investigators and have their involvement in the project. But the project itself, the contract itself, is specifically targeted to that issue. It is hardly a total solution, and I think we are going to have to continue to work in this area and attempt to stimulate more activity.

I think in terms of the concern with making certain that projects are maintained in communities where they have been found to be effective is one again in which we are very much invested. We have worked on the one hand with two Federal agencies in terms of exploring the continuation of service delivery associated with those projects--that is, with the Centers for Disease Control and with HRSA--and CDC

indeed has been enormously helpful in many respects in terms of support, frequently moral, but in some instances, most notably San Francisco, financial support, to allow projects to stay in place.

With HRSA, we have set up some case management systems in New Jersey and Miami to allow those initiatives to stay in place.

I think the most hopeful avenue, quite honestly, and I think the avenue that is probably the most appropriate to explore is one we are going through now with the State agency directors. Working with Bill Butinski, the head of the National Association of State Alcohol and Drug Abuse Directors, I have sent letters to all of the State agency directors in whose States projects are going down, and I am in the process of making the follow-up phone calls that I had indicated I would be making in these letters to them. And I have been able to link up by phone with four individuals, three of whom have promised that they will continue to make funds available for service delivery, and obviously that is something that we will continue to pursue.

Again, I am concerned in this general area with getting the word out, as I was indicating, in terms of

service delivery initiatives that are found effective in leading to behavioral change and indeed seeing to it that the States, who are going to have the lion's share of the dollars, are in a position to follow through and support these kinds of initiatives.

CHAIRMAN OSBORN: We have several Commissioners who have indicated an additional interest. Don Goldman and then Scott Allen--

VICE CHAIRMAN ROGERS: June, could I just interject, because I don't think--could you give a very simple answer to what are the future plans for funding here, because I think that's what Mrs. Diaz was asking. And many of us have heard that after all this enormous effort, these programs are simply being phased out. Is that correct?

DR. BROWN: I would say only in part. The demonstration phase, which was intended to last for a three-year period, is being phased out. That which will take its place, at least in significant part, will be on the one hand a research effort designed to understand the efficacy of these interventions. That is now in place. There is a grant announcement that has been issued, and that is intended to continue through the foreseeable future at least.

VICE CHAIRMAN ROGERS: Are there specific funding plans for those things that have been shown to be efficacious? Are those on the books, or are those just nonexistent?

DR. BROWN: That's what I am saying, that that is where we are working with the States in particular to--

VICE CHAIRMAN ROGERS: They are not there right now.

DR. BROWN: There is not money immediately available.

CHAIRMAN OSBORN: Don Goldman, Scott Allen, Harlon Dalton, then Diane Ahrens.

COMMISSIONER GOLDMAN: As I understood it, the measurements that you are using are basically six-month measurements?

DR. BROWN: Yes--well, again, I should indicate a number of the programs are doing six- and twelve-month.

COMMISSIONER GOLDMAN: I am just concerned about utilizing those kinds of short-term time frames as a basis for making decisions. At least in some of the populations that I know of, including specifically the hemophilia population that I am very familiar with, there are tremendous difficulties and a relatively low rate of behavior change initially, and it may take as long as two or three years of

constant reinforced education over that two- or three-year period before you are able to see significant kinds of behavior change. And I am concerned about evaluating programs based on a six-month parameter when that may not be what is important in the long run.

DR. BROWN: I think both are useful. I think it is useful to understand the extent to which individuals have effected any behavioral changes over the course of six months. I think with drug abuse, if anything, I think we find that there is a decrement in terms of behavior through time, so that it becomes important to understand the extent to which behaviors modified as six months are still in place at 12 months, typically, in drug abuse if anything. But having said that, I think that is a useful strategy.

COMMISSIONER GOLDMAN: But I'm talking about not merely that it doesn't get better by itself, but it requires continued counseling, follow-up, and therapy during that period of time in order to finally achieve that.

DR. BROWN: Well, I think you are suggesting an alternative kind of intervention strategy, and it is one that again, a number of the individuals who are coming in with new grants are going to be exploring in terms of use of, if you

will, booster sessions to attempt to strengthen early results. But again, I think that is a very useful kind of strategy to look at.

CHAIRMAN OSBORN: Commissioner Allen?

COMMISSIONER ALLEN: How many of the 63 projects are in their third year?

DR. BROWN: Well, it is 63 sites; it is 41 projects.

COMMISSIONER ALLEN: Okay, 41 projects.

DR. BROWN: And it is roughly 11, but again, it impacts approximately 15 cities.

COMMISSIONER ALLEN: Okay. What kind of technical assistance are you providing for the States and the local governments in picking up the ball?

DR. BROWN: As I say, I have written in conjunction with NASADAD, so that we have the very real support of the National Association of State Alcohol and Drug Abuse Directors. I have written; Dr. Butinski has promised that he would write follow-up letters as well to the States, and I am calling each one of the States, State agency directors, to discuss with them the specific program that is going down in their State and to encourage their picking it up.

COMMISSIONER ALLEN: You don't have anyone in

particular who is going out to the States to help them walk through the granting process or help evaluate programs and the enhancement thereof?

DR. BROWN: We can only really do that on the telephone. We just don't have that kind of staffing.

CHAIRMAN OSBORN: I think Jim Allen wants to comment in this particular context; then we'll get back to the order of Commissioners.

DR. JIM ALLEN: What you are getting at, the questions that were raised by Eunice and David and now by you, Scott, it is very difficult when we've got the type of agency structure that we have in the Public Health Service. It works extremely well in some areas, and then when you are talking about the transfer to a continuing service type program, it sometimes doesn't work as well.

We are well aware of this problem. We have a working group that is addressing the issue. It includes people from my staff as well as people throughout ADAMHA. It includes people from CDC and HRSA, from the State and territorial health officers, and from NASADAD. We do hope to address the problem. Obviously, it would be nice if we had beaucoup money coming in in the next budget year that we

could not only continue these programs but expand those that have been found effective. We unfortunately do not have that.

On the other hand, what we are trying to do is to look at some of the drug abuse treatment moneys that are available through Beny Primm's programs that he described, and in particular we are looking at developing through his programs, through the Office of Treatment Improvement, technical assistance packages that not only will be able to help those States put into place the continuation programs but also perhaps to expand this type of program to other areas that are interested.

It is not the totally adequate response we would like, but we are well aware of the problem, and we are trying to address it.

CHAIRMAN OSBORN: Thank you.

COMMISSIONER ALLEN: Jim, this is also happening in HRSA when their demonstration projects are ending, the lack of technical assistance and so forth. Are you addressing that as well as just not only the drug issue--you have Beny Primm's office for that--what do we have for HRSA? What do we have when all this money starts drying up?

DR. JIM ALLEN: With the HRSA demonstration

projects, unfortunately we often do not have another source of money such as we had with the drug abuse treatment moneys. I wish I had an adequate answer for you, Scott. We don't, but we are aware of it, and we are trying to work on it, and we hope that the questions and issues raised by the Commission will help us in our struggle to put together the types of resources that are needed.

CHAIRMAN OSBORN: Okay. Harlon and then Diane.

COMMISSIONER DALTON: Dr. Brown, I'd like to pick up where Eunice left off a little earlier. It is nice to see all the lovely black and brown faces in your quarterly newsletter. The truth is, however, that these are the field hands, the outreach workers, the indigenous people, as you refer to them, and the truth is, as I understand it, that for the most part the investigators, the overlords, if you will, are white, and that creates any number of difficulties including the replication of this kind of racial division between top and bottom, which my understanding is from talking to people who are working n your programs has created great difficulties within individual projects. So that it is not just that there is some theoretical problem with the lack of black and Latino investigators, but in fact it is a real

recipe for dissention and for real anger and resentment on the part of the people that you have quite appropriately recruited to do outreach.

A related point I want to make connects up with something Belinda said. She talked about talking to folks who have been drawn into your programs and that found that if they were HIV-positive, there was not much there for them. My sense of what is happening at the street level with your program is that oftentimes the folks at the bottom, these people, aren't very much concerned about providing service. I mean, their involvement is not because they have a primary interest in research, but they want to do something about the problem of AIDS in their communities. The people at the top, who look very different than these people, are concerned about research, in fact, the way in which your projects are structured, and the incentives in them in fact push very much in the direction of research, so there are great tensions which break along racial lines, among other things, between those folks who want to get the numbers and those folks who want to actually do some good now for people with AIDS.

It seems to me that in your presentation today you have perhaps unwittingly mischaracterized the emphasis in

your programs. That is, I think you have led us to believe that your programs are doing more for people in the present than I think they are in practice, and it may just be that the information you get in Washington is not the same as what I am suggesting and what Belinda is suggesting, in which case this is an opportunity for some second- or third-hand feedback, or it may just be that maybe I misheard the presentation, but it has worsened to me.

DR. BROWN: Well, again, I think that all demonstrations are a funny mix in terms of services and research. That is, typically, in the demonstration program about 75 percent of the dollars are for services. Having said that, the grant really is awarded on the basis of the research; that is true, that it is awarded on the basis of the quality of the research, the reason being that we really do want to understand what kinds of interventions can be effective with the populations with whom we want to intervene.

I come out of a clinical background and wandered into research for those kinds of reasons. I don't think I mischaracterize the programs when I say that there really is an overwhelming concern with regard to the service function, not in terms of ignoring the research, but genuinely in an

effort to allow the research to understand what indeed can be useful and what we do want to transmit to other communities in terms of strategies for use in intervening with these populations.

This service delivery is extremely important in these issues. I grant that these programs cannot solve some larger social issues, most notably the underrepresentation of minority group members in terms of the research community and in terms of some other kinds of professional communities. Those are very real problems which need resolutions. But I grant that these programs are not going to be able to solve those programs in terms of being in a position to locate people who simply do not exist in sufficient numbers. I genuinely believe--I would to God they did--I think it would be much better for the program as well as for many aspects of the larger society, of course.

DR. HAVERKOS: Let me just say that we are trying to increase technical assistance and involvement of minorities in a number of programs, through a number of programs that have been recently initiated or enhanced--one, technical assistance to minority investigators to help with grant writing and understanding the process of the grant mechanism,

and 2) we have recently tried to increase the visibility of our clinical fellowship program and our clinical research fellowship programs, and of course are trying to encourage minority applicants in those areas.

So we are trying to enhance those programs. They are coming along slowly, and it is going to take time, even once we train these people and get them into different programs, to actually be the principal investigators on these applications. But we recognize the deficiency there, and we are trying to do some things to build up a cadre of investigators in the minorities.

CHAIRMAN OSBORN: Diane Ahrens has been quite patient. Diane?

COMMISSIONER AHRENS: Thank you.

Dr. Brown, it seems to me your program has demonstrated that the research you have been doing has been really quite effective in terms of prevention, and from what I heard you say, the opportunity to continue will really be at the State level, depending on whether the States choose to fund it. And it may be that Dr. Primm's operation will come up with some money. But I guess to bring a little bit more fiscal reality into this picture, I know that my State is

running a $160 million deficit this year. I think many of the States in which your programs are located are in a similar, perhaps even worse, situation.

So what, realistically, do you think is the prognosis for the States, and how many picking up this program?

DR. BROWN: I can only say that so far the response has really been quite positive. Now, when I say "so far", I am talking about the four State agency directors with whom I have been able to speak, and I will be speaking to approximately 15. Part of it is, of course, that there has been a significant bolus of money that has been given to the States in relationship to drug abuse treatment issues, and that some of that money can be used, and three out of the four people I spoke to are planning on using that money for these purposes.

I don't know what the long-term prognosis is in this area. Obviously, we would be very concerned with making certain that those initiatives that are found to be effective, especially in this terribly significant area, can be maintained. And again, I can only say, as Dr. Allen was indicating, that we are working with both Federal agencies and with

the States to attempt to see that happen.

I don't know what the long-term prognosis is.

CHAIRMAN OSBORN: I have a feeling if you could write the rules, you would write them a little longer than they are right now, and we are giving you some of the heat for that, but we really very much appreciate the time that you have taken to tell us about the programs that have been going on.

I think at this point I will suggest that we adjourn for our lunch break, and Maureen will give us the details of the logistics for the Commissioners in just a second. We do need to start again at 1:30 as scheduled because we want to hear from Don DesJarlais, and then at 2:00 Congressman Green is joining us, and I think that is a rather tight schedule from his point of view.

Maureen?

MS. BYRNES: We'll be having lunch in the same room where we had it last time we met; it is Room A.

[Luncheon recess.]

AFTERNOON SESSION

CHAIRMAN OSBORN: We had hoped that the people from Housing and Urban Development could join us. Remarkably enough, nobody from Housing and Urban Development could manage their schedules to join us. That's all I have to say on that topic.

I don't think it has happened yet, but after a little while, Commissioners will have in front of you a draft of a set of thoughts, a very brief set of thoughts, half a page, relating to something that we sent to you in your packets in anticipation of this meeting which were advance copies of some material that will be appearing in the Journal of the American Medical Association tomorrow. The information has been available to the press for a couple of days and is embargoed for comment until tonight. We thought you would be interested in it, but somewhat similar to some of the other news happenings of recent days, you also may as members of the National Commission on AIDS be asked to comment or to react and so forth. I think that what was included, I believe, in your packets was not only the article that basically says, "It's almost over, folks, so you can relax now," but in addition a couple of editorials that deal very

responsibly with the data that we are more familiar with than that analysis of it, and another article that will appear in the same issue. So there are four different things appearing in the Journal of the American Medical Association tomorrow, and the draft statement that you will get is a quick effort at a very summary analysis of where that stands in relation to the work of this Commission. It is not intended to make you think that, but it is intended to make you know a little bit about what our quick analysis of that is and what a cursory comment would be.

We can certainly talk about that some more, but I wanted to let you know what the reason was for having those items in your packet. I have already received some inquiries from the press and so forth. And since it has been I think everybody's experience that any prediction that the epidemic is almost over immediately takes precedence over any prediction that it is not, it is very likely that you will all be asked to have thought about that, at least to be aware of it. So that's what we are trying to do with that, and I hope that is useful to you.

Yes, David?

VICE CHAIRMAN ROGERS: Let me just comment a little

ah



more fully, because Diane looks very puzzled over there.

This is an article by a very senior statesman in epidemiology, Alec Langmur, who was the teacher of most of the epidemiologists in this country, as head of CDC. So he is a very distinguished man, now in his early eighties--isn't he, Jim--

DR. JIM ALLEN: Yes.

VICE CHAIRMAN ROGERS: I think he trained Jim as well.

But it picks up a formula for predicting epidemics that was early 1800 kind of formula, and in essence suggests that the epidemic peaked in '88, and it is going to be disappearing by '93, and that we will have a total of only about 200,000--I shouldn't say "only"--we will have a total of 200,000 patients with AIDS.

There are some rather careful editorials that are in there, too, but most young epidemiologists don't want to confront Alec too directly. But they do point out that we think we have over one million people who are infected in this country and that it seems kind of odd to suggest we won't have more than 200,000 patients, for example.

Both June and I felt that you, I am sure, were

going to be receiving queries about this, because as June says, this is the kind of thing that is welcomed by people, and they say, "We can all go home; we can shut up shop; we don't need any more dollars," and so on.

So this is a very brief statement which in essence says--well, you'll have it. Tom is putting it together, and it is something that we constructed that we thought we ought to have on hand for those kinds of queries.

Is that enough to--

CHAIRMAN OSBORN: Yes. Jim Allen, thank you for sitting in for Jim Mason.

DR. JIM ALLEN: Thank you.

To me, the important problem with the analysis is that I think it fails to take account of what I believe is overwhelming evidence of continuing transmission of the virus. It uses a formula that is much more applicable to a classical epidemic-type situation in a virgin or a highly-susceptible population, but most infectious diseases have, compared with HIV, a very short incubation time of days to weeks, and with this one, where we are looking at a latency period between infection and onset or diagnosis of illness of years, I think all bets are off. And we very clearly know

that in most of our populations there is still greater or lesser degree of transmission, and in particular if you are estimating it in the aggregate, I think we can estimate fairly clearly that there are at least 40,000 to 50,000 newly infected people each year at the present time. I think because of that fact it totally invalidates the analyses that have been presented here.

VICE CHAIRMAN ROGERS: Why didn't you write the editorial?

CHAIRMAN OSBORN: Well, even--Jim, the 40-50,000 number you just used was the lower end of a range of estimates of new infections.

DR. JIM MASON: Yes.

CHAIRMAN OSBORN: The higher end of that range in that much-mispublicized meeting of October 31st-November 1st was four to five times as many. So the least number that any of the analysts looking at all the data as of October 31st, 1989 felt was the lowest number of new infections per year at the moment, was between 40,000 and 50,000. But the upper range of that set of estimates was more like 200,000.

So it is a troubling analysis. I don't want to take on Dr. Langmur as an epidemiologist, but I don't mind

taking him on as a virologist. And the model that he cites, even in the Journal of the American Medical Association article that we are talking about, is that of a disease called rinderpest in cattle that you may not know much about, but it is the exact analog of measles in people. And he is using, per your inferential purposes, it is entirely accurate to think of this as being looked at as if it were a measles epidemic--which, as you know, has less than a three-week incubation period, a lifelong immunity to follow, and a very clearly developed pattern of insusceptibility of a population once the epidemic has gone through. So that it is virologically about as unlike this epidemic as you could manage to create in terms of its immunologic characteristics, in terms of its transmission characteristics, in terms of its patterns of spread through population. Any of the virologic characteristics that could possibly pertain are different. And it was in 1840 that the curve that he is drawing from was first proposed, and there has been some movement in the biostatistical sphere since then, I am pleased to say.

COMMISSIONER AHRENS: May I--I just quickly read this. Based on what you are saying, based on what Jim is saying, this is awfully mild.

CHAIRMAN OSBORN: It is very mild. We don't want to tell you how to get into the argument. We have given you the background material, and it is very difficult, as David suggested, to get into any kind of detailed argument with a senior statements. I am--

COMMISSIONER AHRENS: Why?

[Laughter.]

CHAIRMAN OSBORN: Go ahead, David.

VICE CHAIRMAN ROGERS: Well, I think this says it, but I don't think we should get into an argument with a whole bevy of epidemiologists who are fighting this. So in essence this statement says: Forget that. We know that there is going to be an enormous new load of patients, and that is what we are concerned with.

CHAIRMAN OSBORN: Charlie?

COMMISSIONER KONIGSBERG: Yes. I think the statement is fine and is appropriately middle-of-the-road without taking issue with that. I think this also points out something that I hope at some later point, such as tomorrow, I will have a chance to discuss--why we need to have some discussion, some experts come in here and discuss the epidemiology of the disease, the projections, assuming that

any of us can understand some of the crazy formulas that are used, because I never have, but I keep trying. Maybe Jim Allen can explain them to me--no, he is shaking his head. But there are differing opinions. I have been in some other conversations in a very different setting where there were almost violent arguments between two Federal agencies about whether there were 685,000 infected or 1.5 million. I came to the conclusion that probably neither one of them knew what they were talking about. Either way it is enormous. But for program planning, it does make a difference, and that is part of what we need to get up on in some of these things. Otherwise we are not in a position to take a position, which is why I think the introductory statement is appropriate.

MR. PERNICK: June, does JAMA welcome letters to the editor?

CHAIRMAN OSBORN: Yes.

MR. PERNICK: Why not a letter from yourself, representing the sense of the Commission?

CHAIRMAN OSBORN: We would be happy to do that. But I think you do want to--I mean, Diane's reaction that this is mild is helpful in a sense, because there are ways and ways of responding, and we'll certainly share with you a

potential response.

Harlon?

COMMISSIONER DALTON: I think one of the things that Diane said sotto voce is that even if the intent of the statement is not to take direct issue with what this says, but to express--what is intended here could be said more forcefully as well--

CHAIRMAN OSBORN: Well, if I write a letter to the editor it will be said more forcefully than this; the sense of the Commission, however, is important in that regard, because if I wrote it as Chairman of the Commission it would want to convey a sense of concern that you all have, which should be based on this rather than on "Trust me, I'm a virologist" kind of stuff.

So if I write it, I will write it from both vantage points; but as a member of the Commission, when I got to that stage in the letter, I would say "The National Commission on AIDS joins me in their concern because of this"--because we already know, without getting into epidemiologic arguments, that the problem is bigger than that analysis suggests and will be an enormous problem for society to respond to. So it is a mix of things. I certainly will not be quite so

softspoken in terms of the bell-shaped curve and so on.

Don?

COMMISSIONER GOLDMAN: Go ahead, Ms. Mason.

COMMISSIONER MASON: I was just wondering--this is probably a tremendous waste of time and energy, but I wonder if we have like editorial opportunities--can we get like an editorial page placement of an opinion by you or co-authored by Dr. Rogers--like a guest editorial feature sort of thing, to kind of counter this in some of the major markets, because I feel that it is going to be something that is going to be with us in the media now as these things go, kind of a wave of it--

CHAIRMAN OSBORN: That's a nice suggestion, and we can explore that with George Lundberg, who is the editor of JAMA. It is not unprecedented in the sense that in an issue of the Journal of the Acquired Immune Deficiency Syndrome that is coming out about today is the article that says that the number of AIDS cases--AIDS cases, specifically--declined compared to expected starting in '87, but then goes on to analyze that that decline was entirely in the context of people who were educated, affluent and able to take advantage of what had gone on, and concludes that treatment has made a

difference--but I think also can conclude that good medical care makes a difference.

To my enormous pleasure, the editor of that journal called me when that was still in manuscript form and asked if I would write an accompanying editorial as myself, but from the vantage point of the public policy implications of misunderstanding that article.

So I have written an editorial that basically says we now know that it matters more than--we now have proof that as of 1987, it mattered more than ever who you were, who you knew, and how much you could afford as to what your outcome was going to be. That is the punch line in the editorial that will go with that article in the Journal of the Acquired Immune Deficiency Syndrome. So there is that precedent about to appear as we speak. And I think we could ask George Lundberg if we couldn't--especially with the Commission all nodding the way they are--if we couldn't respond in the name of the Commission.

COMMISSIONER MASON: I was thinking, too, Dr. Osborn, of the major market in these papers, like the Times and the Post, and the Ohio County Times News--one of the leading papers in the country--I know as a former journalist

that lots of times people are desperate for things to fill out their editorial pages. It may not be as taxing a business in Washington as it is in Ohio County, but I think that with the right kind of connections--and I have known Tom to be able to really pull out some aces at times when we need them. I think we could chat up some of these people on these editorial boards and say, can we just write an opinion piece for you, blah, blah, blah, for your Sunday paper, because I really fear that we are going to be seeing a whole new way which is feeding into the whole backlash against AIDS, and there are just going to be more obstacles and barriers in the road for us unless we kind of strategically plan to counter that from a public relations standpoint.

CHAIRMAN OSBORN: We'll see what Tom can chat up. I think your suggestion is very wise.

Scott next, and then Don.

COMMISSIONER ALLEN: Just a point of content. If you are going to work off this, the last sentence, I would hope we would add education and prevention.

CHAIRMAN OSBORN: Yes, I was planning to do that--

COMMISSIONER ALLEN: I think that is very, very important. The last phrase, "to stop the spread of infec-

tion", may imply the cure and vaccine rather than the education and prevention that we really need somewhere in there to aggressively set it out.

CHAIRMAN OSBORN: Yes.

Don?

COMMISSIONER GOLDMAN: I did not think it was terribly responsible of the AMA to have given credence to that article. It just didn't make any sense. If the article's authors are correct, I don't understand it, because I think all of us know the 959 victims of AIDS that are predicted in 1995, we'll probably end up knowing them all, and I don't know whether or not the author is suggesting that it is only afflicting people that we know.

The question I have about the statement is that I am not even sure whether or not the first phrase of the sentence even characterizing the suggestion as a "debate" dignifies it to a degree that frankly, I would feel uncomfortable in giving it a level of deservedness. And just because somebody is eminent and comes up with--I can remember years ago, in my own limited way--I had a little computer program--dealing with the curves, and I found 97 curves that could fit the epidemiological pattern in AIDS among people with

hemophilia, some of which peaked and some of which did not peak. And to say that you can find a statistical pattern that applies in some infections and to an incomplete set of data, it just doesn't even make any real good sense. And I would think that probably were it not for the renowned nature of the author, that probably would not have been given much credence even in terms of having been, as the publication suggested, otherwise.

VICE CHAIRMAN ROGERS: Don, I think it is a little more complicated than that. This man has been right a surprising number of times. Bear in mind this is a peer-reviewed journal. I think he is dead wrong. This is a peer-reviewed journal, a thoughtful editor. I am startled that it was published, but there were clearly some tough people who reviewed this. I think they fought over it over the last year, almost two years, before this was published. I have seen it before, and probably a number of you have. I am disappointed that they published it, but nevertheless it was a group who felt that the science was not that bad. And I think we are foolish to try and get into that argument. There are epidemiologists all over the country arguing this thing. I'd say just set it aside and say let them go off and

fight. Our concerns are that an awful lot of people are going to get sick and die of this disease, and that's what we are worried about. If we get into the argument about this is bad data, then there will be another whole series of letters to the editor saying no, this is good data--and then we've got to go back.

I think we should just say forget that, and let them worry about it.

COMMISSIONER GOLDMAN: I agree, but what I was saying is in terms of the statement, the first sentence, there is really no need for the first sentence in the sense that the question is being asked in the context of the question that the epidemic may have peaked, and the rest of it simply follows from that without dignifying the debate among the epidemiologists in getting us involved in it. My point was simply to stay away from it entirely.

CHAIRMAN OSBORN: In the context of what you have in front of you, I wasn't sure whether we would have time for the discussion that we have had in a timely way before the evening news, which is when this is going to hit. So that I would not be concerned that we would use the specific language of this so much as to try and let you know in a very

quick way what we were thinking about, coming from at least a relevant technical direction. Presenting you with a couple of papers and a couple of editorials from JAMA without comment did not seem fair either, since not everybody is in the habit of reading JAMA all the time.

So we thought that something like this, just to give you a very softly-worded position that we would suggest was appropriate, was all we wanted to do with this language.

I assure you--you know me--I'll start from scratch and all that stuff.

Don DesJarlais?

COMMISSIONER DESJARLAIS: I think if we are going to comment on this publicly either as individuals or as a Commission, we ought to pay attention to David's point that it is not as if this science is totally, absolutely wrong. This model is actually very well-developed. It fits many epidemics, some that are almost purely behavioral like drug use--this model is not too bad for applying to drug abuse epidemics. So that we should be aware that this is not totally, absolutely wrong, that science progresses by trial and error; that if everything published in a scientific journal were always right, then you would do science once and

then quit, and you wouldn't ever have to do it again. But science really progresses by trial and error, and I think there is a big error in this. I think in particular if you look at the last sentence of their abstract, they talk about the cases going down to an endemic level, or sort of a constant steady state, that they believe will occur at a low level. I think that that is really where we should specifically disagree; we do not think it is going to be at a low level. All of the behavioral epidemiology indicates it is going to be an unacceptably high level. So that it is not as if they are crazy people, and we shouldn't treat them as if they are crazy people, but there is a specific place where we have good reason to disagree, and that is the endemic level, the number of average future cases per year for the rest of the world.

CHAIRMAN OSBORN: Thank you. I think that is a very helpful point. We will certainly be sharing with you.

Congressman Green has arrived--I think with considerable difficulty from traffic--and I know that you had a tight schedule even before the traffic got you, so let me welcome you, and ask whatever time you have that you can share with us, we'd be very pleased to hear your comments.

We were very glad to have you with us before, and thank you for coming back to talk with the Commission.

STATEMENT OF THE HONORABLE S. WILLIAM GREEN,
REPRESENTATIVE IN CONGRESS, STATE OF
NEW YORK

MR. GREEN: Well, thank you very much, and I do appreciate the opportunity to appear before the Commission as I appreciated the opportunity to join you for part of your visit to New York, for which I also thank you.

I am concerned basically with the shelter for people with AIDS, and I guess my attitude is to some degree affected by the situation in New York City, but of course that is a significant part of the AIDS population in the United States at the moment.

As you are probably aware, we had a very stern policy in terms of trying to eliminate empty beds in hospitals and nursing homes in New York State, and that policy was successful for quite a number of years in holding down the increase in hospital costs in New York as compared with other parts of the country. Unfortunately from my perspective, the State persisted in that policy after it became clear that the AIDS epidemic and then the crack epidemic were going to place a call on hospital and nursing home beds that, if one kept closing them, could not be met, and that is essentially the

situation in which we find ourselves today.

We literally have a situation where the patient is upstairs, now past an acute phase, ready to be moved on to some other lesser facility that does not exist, and as a result, there are people in beds outside the emergency room downstairs who can't get a bed upstairs. The effect also under the DRG system, even with the provision for outliers, is devastating on the hospitals because they really don't get properly compensated for the extra time that that bed is not in use.

So I think we really do have to start looking to see what can be done to provide some form of shelter for people who do have disabilities as a result of AIDS but do not need the acute care bed in the hospital.

I had hoped that we had made a start at that in last year's Veterans/HUD/Independent Agencies appropriations bill. As the bill left the House, we had a specific provision that 250 units to be funded under the Section 202 program for nonprofit housing for the elderly and the handicapped would be set aside for persons with AIDS. In the Senate, that provision disappeared on the floor, but there was an amendment offered by Senator Helms which specifically provided, and I

quote: "persons disabled as a result of infection with the human immune deficiency virus shall be considered eligible for assistance under Section 202 of the Housing Act of 1959."

In the conference committee, that language remained, but in the report, though not in the appropriations language, we did ask HUD to provide 250 units of the 202 appropriation for AIDS purposes.

I am sorry to say that in regulations published last week by HUD, which are the first step toward implementing this fiscal year's 202 program, although the Helms language was quoted, there was no provision made for how the 250 units were to be implemented, and in fact there was a specific statement that they would not permit housing to be created all of whose occupants would be people with AIDS.

I checked with the Department, and that was a very preliminary stage of the process of developing the regulations, apparently necessary under the Paperwork Reduction Act. I have never quite understood why the Paperwork Reduction Act involves all these additional publications in the Federal Register, but there it is. And I was assured by the Undersecretary that as a result, the draft implementing rules which were included with that publication had not in

fact cleared the Secretary's office as they would if they were in fact offered as results rather than as Paperwork Reduction Act publications. So there remains some hope.

But I think the position that one should not have housing exclusively for persons with AIDS is not very realistic in view of the circumstances that we all know and the need to focus services on people with some very special problems. There is certainly plenty of evidence around the country that there are developments specialized for persons with AIDS. The New York AIDS Consortium put out a booklet which gives examples around the country, and of course in New York City we have Bailey House, as you are aware. I might add that we had some problems when that was set up, but the Federal Government started to take the position that people under the disability insurance program could not be funded because this was a city-financed institution. There is language obviously trying to deny people in prisons the right to collect benefits under the Social Security Act, and one understands that, but it was plainly not intended to deal with this kind of situation, and we did ultimately get that straightened out.

But it seems to me that there is great validity for

this kind of housing for persons with AIDS. Certainly in the past, the 202 program has been used for people with one kind of disability with special needs. There was such a facility built in what was part of my district after the '82 redistricting, one block outside my district, for people who are blind; there is another facility in my district that is half for elderly, half for deaf people. So that I think there has been recognition of the need where there are special types of cases to have housing where you can focus resources on one kind of disability. And certainly, if there is ever a case for it, it seems to me that the problem of people with AIDS is such a case.

So I guess my basic purpose in coming here today is to urge the Commission to take a look at this whole problem of housing and shelter so that we avoid this backing up of people in hospitals because there is no suitable facility for them or that will take them after the hospital stay. Plainly, the number of these people is going to increase, and with the ability of AZT and perhaps DDI and other drugs that may be coming along to prolong life for people with AIDS, I certainly think we are going to need more housing of this sort.

One other area that does concern me is the whole question of reimbursement of hospitals for persons with AIDS. I mentioned the problems we had under the DRG system. I am even closer to the situation in the veterans' hospitals because the Veterans/HUD/Independent Agencies Appropriations Subcommittee, where I serve as ranking Republican, also handles, obviously, the VA medical system.

I think up until now, both HCFA and the Department of Veterans' Affairs have taken the position that one should not create a separate DRG for AIDS, and I don't quarrel with that conclusion if we could see some other form of formalized recognition of the problem that would measure the additional burden placed on institutions, the DVA, in allocating resources to its veterans' hospitals and HCFA in terms of making payment to civilian hospitals for persons with AIDS. At the present time, it seems to me the system is quite ad hoc, without any real way of measuring how much additional funding there ought to be, and I have some gut feeling--and again I can't say that I've got any statistical evidence to give you--that that is short-changing those institutions with heavy AIDS loads. So it seems to me that that is another area that ought to be explored.

I'd be happy to answer any questions you might have.

CHAIRMAN OSBORN: Thank you very much.

I mentioned before you arrived that we had invited somebody from Housing and Urban Development to come and talk with us as well, and they seemed to be extremely short-handed because there was no one who was available to come and talk with us. So we are very appreciative of some of the insights that you have given, and I think the Commissioners may have some questions in that regard, as well as the specific topics that you brought up.

I hope you'll let us know when your time constraints become urgent--

MR. GREEN: Well, when this beeper goes off, I've got to run.

CHAIRMAN OSBORN: That's very helpful. Okay. With everybody knowing that, let's see if the Commissioners have questions.

Diane Ahrens.

COMMISSIONER AHRENS: Congressman, I think there is a real problem here when we cannot address the issue that you have presented to us to the appropriate authorities, and I am wondering if you could suggest how we urge or cajole--or we

have invited--the HUD folks to come and talk to us. I mean, this is very critical.

MR. GREEN: I will certainly encourage them and even offer to cover their travel expenses from Southwest to here in the next appropriations bill, if that's their problem.

[Laughter.]

CHAIRMAN OSBORN: Don DesJarlais.

COMMISSIONER DESJARLAIS: First, Congressman, as a resident of New York City, I'd like to really compliment you on your efforts in the AIDS area. They have really been quite helpful. And then, really, to ask a follow-up question--drawing on your expertise as an effective political leader, clearly, one of the great difficulties in housing for people with AIDS is community rejection of setting up housing. Even when you've got the money and the staff available, there are tremendous difficulties.

I would like your thoughts on what this Commission might do to address that community resistance and anything that we might do to diminish it, because it clearly is going to be one of the major problems not only in housing, but in providing treatment centers for people with HIV infection.

MR. GREEN: Well, I wish I had some simple answer

to the "not in my backyard" phenomenon which afflicts so many efforts including ours with AIDS. But I'd have to say that at least in New York City, I would guess in San Francisco, and some of the other cities where the problem is concentrated at the moment, there are some neighborhoods at least where the problem is so evident and so much viewed as a problem of neighbors that the housing is acceptable. Certainly, there are large parts of Manhattan where I would consider that to be true.

So, while I would agree with you that there are many places in the country where it is going to be a problem, and we have the same problem with mental health and drug treatment and all the rest, I don't see that, at least in terms of the numbers of units we are talking about at this juncture, as the pressure point in the program. That's not a total answer to your question, I realize, but again I don't see that as the critical path at this juncture.

Bailey House, for example, as far as I know, aroused no community opposition whatsoever and was quite happily received by its community.

COMMISSIONER DESJARLAIS: Although the residence that the Catholic Church was trying to open up in northern

Manhattan ran into rather stiff opposition.

MR. GREEN: Well, that's right. The Harlem residence was more of a problem. I hope that Mayor Dinkins will take a second look at that and that this is simply a pause for him to get hold of the problem rather than a final rejection on his part.

CHAIRMAN OSBORN: Commissioner Rogers?

VICE CHAIRMAN ROGERS: Congressman Green, as another New Yorker, let me thank you for your efforts. I thought it might be useful for the Commission to put that Bailey House in perspective in terms of needs in New York. That is 44 beds at a time when we project at this moment we need about 2,000 of those kinds of beds. So we should push in every way.

MR. GREEN: Yes.

VICE CHAIRMAN ROGERS: We are sadly behind. We are scandalously lacking in those kinds of beds in New York City. And I know your efforts, and I share your concerns.

MR. GREEN: And obviously the 250 units spread nationally, even with an instruction in the report that they go in those communities with the highest AIDS incidence and the lowest housing vacancy ability, would target it to some

degree; it is still very small compared with the overall need, and I certainly am aware of that.

CHAIRMAN OSBORN: When I took over as Chairman of this Commission, I managed to get rid of almost all the other hats I had except I continued to serve as the Chairman of the National Advisory Committee for the Robert Wood Johnson Foundation AIDS Health Services Project. And in the invaluable experience that we gained visiting around, I could add to your comments that I think in every community where the Robert Wood Johnson projects have been up and going, the conclusion has been made that housing is at the base of some of the serious troubles that otherwise could be resolved.

So I think it is a very pervasive problem that takes different forms in different communities. But it is nevertheless quite pervasive--and I hear your beeper.

Thank you very much for your efforts in coming to join us.

MR. GREEN: Thank you.

CHAIRMAN OSBORN: Don DesJarlais has been patient with us in rearranging him at least twice on the schedule. As he takes his new seat, let me say that I have had the privilege of working with Don in several contexts and have

had intermittent opportunities to hear his expertise in the area of illicit drug use and related matters, and he serves as a source of both inspiration and information for me, ad hoc, a lot.

A number of the Commissioner having either heard me say that or others have complained that we never got a chance to hear a systematic presentation from Don, so we have asked him to do double-duty and to talk to us this afternoon, and this will allow us to continue and enrich the discussion of this morning.

Thank you very much.

STATEMENT OF DON C. DESJARLAIS, PH.D., NATIONAL COMMISSION ON AIDS

DR. DESJARLAIS: Thank you, June.

Given that I feel I have something of a captive audience, I can be scheduled where need be. And I do very much appreciate the chance to make a sort of formal review of the current state of the HIV epidemic among drug users, particularly people who inject drugs.

Something in contrast to what we heard this morning, I will be spending a considerable amount of time talking about what is being done in other countries, because I think it is very important for us to be able to learn about the AIDS epidemic among people who inject drugs in Western Europe and in Southeast Asia and in South America.

Too often when people think about drug use, they think only about their own neighborhood, their own city, or at most their own country. There is little systematic consideration given to what other countries are doing and the potential effectiveness of changing some traditional ways that an individual country may have with respect to dealing with drug problems.

The first point I want to make--and it is somewhat

relevant to the JAMA materials that were distributed earlier--is that the official AIDS statistics for i.v. drug users greatly underestimate the seriousness of HIV infection among people who inject drugs.

From our studies done in New York, from a couple things Herb Kleber mentioned this morning from his work in New Haven, and from studies in New Jersey, it is very clear that development of AIDS is not the only outcome of HIV infection among drug users; that drug users with HIV infection are very prone to developing other infections such as tuberculosis, endocarditis, bacterial pneumonias, and that many of those HIV-infected drug users will die from these other infections before they develop AIDS, so that they never get counted in the AIDS statistics, but they are clearly dying from complications of HIV infection.

Based on our New York City estimates, we would estimate that for every one drug user who develops AIDS, there is another drug user, HIV-infected, who dies before he or she develops AIDS, so that the official AIDS case statistics for i.v. drug users are probably missing half the fatal infections.

I would also like to point out that one of these

other infections that is not currently considered CDC definition AIDS is tuberculosis. This causes particular problems because tuberculosis is a communicable disease, transmitted through casual contact. We did visit the TB ward at Bellevue a couple of weeks ago. We have seen massive increases in tuberculosis associated with the HIV epidemic in New York and New Jersey, and we are now starting to see some evidence for secondary spread of that tuberculosis such that it's not just the people who are HIV-infected who are coming down with tuberculosis, but there is now some preliminary data indicating that they are spreading tuberculosis to people who are not exposed to HIV.

A second point that I would like to make is that there is the potential for very, very rapid transmission of HIV among people who are injecting drugs. In New York City as best we can determine, the HIV exposure rate went from about 10 percent in 1978 to about 40-50 percent of the drug users exposed in 1983, a period of about five years. In Edinburgh, it went from introduction of the virus to about 50 percent of the drug injectors exposed in a period of about two years. In several Italian cities, including Bari, Milan and the Island of Sardinia, it took about four years to go

form 10 percent sero-positive to 50 percent sero-positive. In Bangkok, it went from about 2 percent sero-positive to about 40 percent sero-positive in a period of about 18 months. So that there is the potential for very, very rapid spread.

Cities in the U.S. and cities throughout the world that presently have very low levels of HIV infection may be sort of sitting on a time bomb that will explode if proper prevention programs are not instituted.

And a third point I would like to make is that there is widespread evidence that drug injectors have changed their behavior because of concern about AIDS. Earlier today we heard that people who may die from their next injection of drugs are not necessarily concerned about dying five or ten years from now from AIDS. The evidence from not only United States studies but from European and Southeast Asian studies is that basically that is not true; that AIDS is a very different way of dying than the traditional drug overdose. In the traditional drug overdose, you are not feeling any pain; if anything, you may be either comatose or euphoric; it is relatively quick, it is certainly painless, and it is basically individual--that you may die, but it is you dying.

AIDS is really quite different. Rather than being painless, AIDS often involves a considerable amount of physical pain that can be extended over months to years, and AIDS also is not an individual disease. If you are dying of AIDS, there is a very good chance that you have transmitted that disease to friends, to relatives, to your wife, to your husband, to your children. So psychologically, it is very, very different for a drug user to develop AIDS than it is to die from an overdose. If you die from an overdose, that's you dying. You do not believe that your dying from an overdose is going to kill your wife and your children also.

And the fourth point I would want to make is following up on that point about drug users having changed their behavior, because AIDS really is different from overdose deaths. There are probably about 200 studies now indicating drug users have changed their behavior because of AIDS. There are studies of drug abuse treatment, indicating that people brought into drug abuse treatment programs, with all the faults we heard this morning, those programs have reduced the HIV infection levels. There are studies from New York and studies from Sweden showing that if drug users came into treatment, stayed in treatment, their chance of being

exposed to HIV is somewhere between one-third to one-half what it would have been if they had not come into treatment.

So that we do have good studies of drug abuse treatment, looking at HIV infection levels of people in treatment versus people who had not come into treatment, and showing very largescale differences in favor of those who came into treatment--that is, with all the faults and problems we heard about this morning with respect to the imperfections of drug abuse treatment.

Second, there are a large number of studies showing efficacy of safer injection programs. Barry Brown presented some data this morning on the use of bleach and the use of outreach programs to reduce HIV risk behavior. I won't review that. Rather, I'll talk about some of the European and Australian studies that have focused on safe injection.

Those programs have involved either sterile syringe exchange programs, where drug users bring in their used injection equipment and exchange it for new sterile equipment, or simply over-the-counter sales of injection equipment.

With respect to exchange programs, there are exchange programs now in most Western European countries, in Australia and New Zealand. In those programs they typically

get somewhere between a 50 to about an 85 percent return rate for the used injection equipment. A side benefit of that is that they then can provide for safe disposal of potentially contaminated injection equipment.

The exchange can also serve as a contact point for referring drug users into drug abuse treatment and referring them for other medical problems and other social services they may need.

The evaluation of the exchange programs indicates that they are well accepted when they are basically user-friendly; when there are open hours that are convenient to the drug users rather than necessarily most convenient to the staff; when they take a nonpunitive approach as opposed to a punitive approach, accepting of the drug users as human beings deserving of dignity.

In terms of the effects on the transmission of HIV, all studies of syringe exchange programs have indicated reduction of AIDS risk behavior. The studies in Amsterdam are by far the most advanced, indicating since the largescale expansion of the syringe exchange in the City of Amsterdam, HIV sero-prevalence levels have basically stabilized at approximately 30 percent sero-prevalence.

In Amsterdam, they expanded their syringe exchange from 100,000 sterile needles and syringes distributed in '85 to 700,000 per year distributed currently. During that time, as I mentioned, HIV sero-prevalence has stabilized. The number of people injecting drugs in the city has also stabilized. It did not increase. It is between 2,500 to 3,000 in the city as a whole. And the number of drug injectors coming in for treatment, either their methadone treatment or their drug-free programs, has also stabilized. The expansion of the syringe exchange has not kept people out of treatment nor has it led to any increase in the number of drug users in the city.

Clearly, it is going to take considerably more research to know how effective syringe exchanges are ultimately in reducing the spread of HIV. Amsterdam also has treatment on demand so that clearly it is not the only thing being done to reduce the spread of the virus in that city. But it is clear from the Amsterdam research so far, as well as the rest of the European and Australian studies, that there is no evidence at all that sterile syringe exchange programs are associated with any detectable increase in levels of drug use or the number of drug injectors in the

city.

In addition to the exchange programs, several countries have simply provided for over-the-counter sales. Most places that have syringe exchange programs also provide for simple over-the-counter sale of needles and syringes, so the two should not be thought of as forced choice, doing one or the other. Amsterdam, England, Australia and New Zealand also provide for simple over-the-counter sale. That does not require bringing back the used equipment, but it does require then purchase of the sterile injection equipment.

Evaluations have been conducted in France and in Scotland and in Austria of these over-the-counter sale programs. They find that they are quite well-accepted by the drug injectors. The major difficulty seems to be AIDS education of the pharmacists to get pharmacists' cooperation in the prevention program; while it takes some difficulty, it certainly can be done.

In terms of the program in Innsbruck, where prior to AIDS the pharmacist would only sell sterile injection equipment in lots of 100 or more, so relatively few drug injectors would come in to buy sterile injection equipment, they did do education of the pharmacist, they got the

pharmacist to agree to sell individual sterile needles and syringes. They also conducted AIDS education and counseling with their drug users, and the HIV infection rate in Innsbruck has also stabilized at about 30 percent sero-positive.

To summarize the current state of knowledge with respect to AIDS prevention programs for drug users, we have seen much more behavior change than anybody assumed or believed or would have predicted prior to the AIDS epidemic. The traditional image of drug users is that they will not change their behavior. Very fortunately that has not held with respect to transmission of HIV. We have seen largescale behavior change. But that has depended upon both knowledge of AIDS, belief among drug injectors that it is a local problem--it is not just something happening to gay men in San Francisco, but it is happening in their community. It is also dependent upon means for behavior change--either availability of treatment for people who are going to stop or greatly reduce their drug injection, or some means for safer injection for people who are not coming into treatment for various reasons.

A third and final point with respect to prevention programs for drug injectors--there is a need for long-term

follow-up; that AIDS prevention with drug users, similarly for AIDS prevention among gay men, similarly for AIDS prevention among heterosexuals in general, is not something you do in one half-hour, and then you move on to the next city or do something for one month, and then you move on to the next city. There is a great potential for people relapsing back to high-risk behavior. As some of the speakers mentioned this morning, it really is a long-term effort, perhaps for the rest of the epidemic. You need to establish a presence in the community to change behavior and then maintain that presence indefinitely. You need to continually reinforce the desired behavior--either people not injecting or people practicing safer injection. Preventing AIDS among drug users, like other groups, is not something you do once and then you move on. It rather requires a continued commitment. And in terms of the United States, we are now starting to get into that problem of how are we going to continue the prevention programs that were started up by NIDA over the last several years. They were started as research and demonstration projects. There is some real evidence for their efficacy, and we are now reaching the critical question of how are we going to continue those efforts. Personally, I

don't think that middle-level NIDA staff are going to be able to solve that problem; that may really be a responsibility of this Commission in terms of finding ways to continue these prevention efforts for the indefinite future.

Thank you.

CHAIRMAN OSBORN: Thank you very much.

I think a lot of the Commissioners will have questions. There is one that I wanted to start with because you, I think, were very instrumental in calling it to my attention--this is a comment, but I'd like you to comment on it and see if I have phrased you properly--in addition to the fact that in the very wide experience that has been gathered now with either needle exchange or analogous programs, you do not increase the frequency or prevalence of substance abuse; you do in fact, however, evoke a refreshed need for primary care on the part of people who are caught up in the pattern of illicit substance use.

I am under the impression that that is a very frequent phenomenon, and I wondered if you could comment on that because that was part of what was coming out this morning, was that there was some dissociation between the research intervention focused narrowly on substances and the

need of people caught in that pattern of behavior and being dealt with in a largely legal system for any kind of primary care.

Could you expand on that just a bit?

COMMISSIONER DESJARLAIS: Yes. Personally, one of the greatest difficulties of doing AIDS research in the drug abuse field is what do you do with the tremendous variety of needs that your research subjects have; that you have your outreach workers in the street, distributing bleach, distributing condoms, making antibody tests available. You are then faced with the problem of the drug users who then say, "Yes, thank you for the bleach. I'll use it. But what I really want to do is stop using drugs. Can you get me into a drug abuse treatment program?"

And while there may be approximately 400 open slots in the City of New York, you can fit a few individuals in--you can sit down on the phone and make phone calls and find an opening or find an admissions appointment where somebody failed to show so you can rush your person in, but that's at an individual level. There is nothing you can do at the system-wide level.

Then there are the types of Catch-22s that I

mentioned earlier this morning, that some services require participation in other services. For many of the HIV support groups for sero-positive people in New York, they require that a person be in drug abuse treatment if they have a drug abuse problem, because they don't feel they have the expertise to manage people who are not in treatment. So that you then find people who can't get into an HIV support group because they can't get into a treatment program first.

So that the greatest personal difficulty in doing these research studies is what do you do when you uncover all these needs, and your research budget is totally inadequate to meet those needs, and trying to meet them by referral is clearly also inadequate because the system is so overloaded.

The positive aspect of that is that in doing bleach distribution outreach work, safer injection programs, people have really been finding that sending an outreach worker out to talk about protecting health seems to stimulate a desire to quite injecting drugs among the people receiving the outreach. For many years, they have simply been told "What you are doing is bad, and if we catch you, we are going to lock you up." Now they come across the experience of somebody coming out and saying, "Your health is important.

Something needs to be done to make sure that you don't get sick and die." That sort of breaks the mindset traditionally held by the drug user to the authorities in general and creates much more openness to think about going into treatment, that they will not necessarily be punished for going into treatment, but there may be genuine concern about their health.

CHAIRMAN OSBORN: Commissioner Rogers?

VICE CHAIRMAN ROGERS: Dr. DesJarlais, you are a pleasure to listen to. I wanted to write this down, and you can answer this or not answer this as you prefer. But it seems to me your testimony on what works, on what is effective, and the enormous worldwide evidence you gave us--and I wrote these down--you said it must be user-friendly; it must be nonpunitive; it must be treatment with dignity. That sounds absolutely 180 degrees off what we heard from Dr. Kleber this morning.

Is it possible that they haven't read any of that evidence, or are they flying in the face of it? How do you like that for a question?

COMMISSIONER DESJARLAIS: I think that there is communication occurring between Dr. Kleber's office and

people doing AIDS outreach. I think that there are structural constraints on that communication, including national and international issues.

VICE CHAIRMAN ROGERS: Thank you for your non-answer.

COMMISSIONER DESJARLAIS: I at least avoided it as well as questions were avoided this morning.

[Laughter.]

CHAIRMAN OSBORN: Harlon?

COMMISSIONER DALTON: You are quite the diplomat.

I have a couple questions, Don, one smaller than the other. The small question--you indicated that in at least some European countries or cities, the question of how to deal with clean needles is not a forced choice, that one can do both needle exchange and also making needles available over the counter.

I guess I was curious about whether there have been any studies in countries or cities where both of those are happening, and which is more effective.

COMMISSIONER DESJARLAIS: Actually, almost all of the studies have been in locations where both are occurring, and there is a sense that it is not one or the other, but

rather you should be doing both. The studies from Amsterdam would indicate that more than half of the drug injectors in the city are using the syringe exchange program, but that there are qualitative differences in people who will use the syringe exchange program versus people who prefer to go to a pharmacy. Going to a syringe exchange program requires some form of self-identification as a long-term drug injector, and typically, people who come into syringe exchange programs have been injecting for a very long period of time. They sort of recognize that this is a long-term behavior pattern and a problem. People who are relatively new to drug injection are less likely to go to a syringe exchange program where they may be sort of semi-officially identified. They do not think of themselves as engaging in this behavior on a long-term basis, and they are very wary of showing up any place that is run by officials, where they may be sort of identified as drug injectors or may even have to confront a self-identification question of, you know, am I really into this on a long-term basis versus is this something I am experimenting with.

So the syringe exchange programs tend to get the very experienced long-term injectors. Other, less identified

ways, such as over-the-counter sales--or some cities now such as Copenhagen simply have vending machines where you go up and put your coins in and the syringe comes out--seem to get people who are at an earlier stage of their drug injection career.

COMMISSIONER DALTON: That's really helpful.

The other question has to do with how readily we can borrow from the European models. Obviously, when we talk about altering behavior, we are talking about very culturally complicated stuff. The concern that I have responding to the question of whether making needles increasingly available is going to increase the attractiveness of addiction or the number of addicts--while I am not inclined to believe that that is the case, it is not clear to me that we can immediate-ly transpose experience from European countries to the United States in that I would think that what makes addiction attractive in one country as against another, or the kinds of social supports there are for giving up addiction in one setting as against another, or the extent to which addiction is ringed with a punitive social response in one country as against another all affect whether or not we can simply transfer the data and experience.

So I want some help with that.

COMMISSIONER DESJARLAIS: Yes. There are strong national or cultural determinants in patterns of drug abuse. Drug abuse does seem to be an almost universal phenomenon in human societies, that every culture that has had access to drugs as psychoactive chemicals, has tended to use them and had some percentage of people clearly misusing them. And there is great variation across societies. But there does also seem to be an almost cross-cultural for at least developed countries pattern developing. Certainly, the AIDS risk reductions are very, very similar across countries.

There are some early studies on a very limited basis of sterile syringe exchanges in the United States. The data looks very, very similar to the European data. Clearly, the biggest difference between the United States situation and European situations is that in this country there is an over-representation of ethnic minorities involved in injecting drugs that is not true for the Australian or the European situation. In Europe and in Australia, the people injecting drugs and the people making the political decisions about what to do about it are from basically the same ethnic groups. There is clearly stronger empathy, and ethnic groups

are not being blamed for and stigmatized for the drug problem. So there is a great difference in terms of the cultural dynamics, and I would agree that we cannot simply transfer results because we have a much more complicated situation here with certain segments of our population traditionally being scapegoated around drug abuse problems, and the potential for that to really synergistically increase stigmatization and discrimination, that could lead to not only poor provision of services for drug abusers, but to scapegoating of whole ethnic groups because of the drug abuse problem. That really is the biggest difference and makes our situation much more complicated compared to the European or Australian situations.

CHAIRMAN OSBORN: Scott, then Jim Allen, then Eunice.

COMMISSIONER ALLEN: Don, the term "civil containment" came up this morning.

COMMISSIONER DESJARLAIS: Commitment, civil commitment.

COMMISSIONER ALLEN: Or civil commitment--whatever--I didn't see much difference. Could you explain to me pragmatically what that means to our system and also your

philosophical?

COMMISSIONER DESJARLAIS: Okay. There are two forms of civil commitment with respect to drug abuse treatment. One has been for people who have been found guilty of a crime and are given an alternative of going into drug abuse treatment or going to prison. Some of them will choose prison; the majority will choose going into drug abuse treatment. And it is with a judicial order that if you leave your treatment program you will then go to jail; that your sentence is basically suspended pending successful completion of a drug abuse treatment program. If you then leave the treatment program, you go to jail.

There have been other programs based not on being adjudicated of a criminal offense, but simply being a drug user, that if you don't stay in treatment, you'll go to jail. Clearly, within our legal constitutional framework, the first type is much easier to justify than the second type.

In terms of the success of these civil commitment programs, they do increase retention in treatment if there is effective follow-up. If the person leaves treatment and then actually somebody comes down and follows them up and puts them into jail, that does tend to keep people in treatment.

The problem is that that is very, very labor-intensive to track down people who have left treatment. They are not going to come knocking on your door, saying, "I don't like that treatment program; I want to go to jail."

And given our present overload in the criminal justice system, it is really unclear where we would find those extra parole or probation officers to track down people who have left drug abuse treatment programs. Right now we do not have the capability of tracking down people who did not show up for their trial or are known to be committing additional offenses while on probation. I mean, our basic way of keeping track of people on parole and probation in most large cities is waiting until they get re-arrested. So that it is unclear how a civil commitment system would work without huge amounts of additional dollars to double or triple the number of parole and probation officers.

COMMISSIONER ALLEN: How does one enter the system on the second kind, just being a drug abuser himself or herself, without being arrested?

COMMISSIONER DESJARLAIS: One could receive treatment in a hospital emergency room, and the treating physician could note evidence of a drug treatment problem;

that, clearly, for an overdose would be the easiest one. One could tie it into welfare payments; often in welfare payments there is determination of whether or not there is a drug problem.

There are various ways in which people who have drug problems become known to the system without legal evidence that they have committed a specific crime. So it is possible to identify people with drug problems without having evidence of them committing any specific crime.

Clearly, if you set up that type of civil commitment, you would greatly increase the incentives people would have to hide their drug problems.

COMMISSIONER ALLEN: Do you find that developing out of drug testing and workplace issues? Is this hypothetical, or is this actually happening? That's my question. You keep saying "could"--is it?

COMMISSIONER DESJARLAIS: Okay. Right now it is sort of happening on paper in some jurisdictions. It is not happening on an effective level, really, in any jurisdiction on any sort of large scale, because it is a very labor-intensive, costly type of program to set up. And right now, we are incapable of providing treatment to everybody who

voluntarily comes up and asks for it, much less trying to find people who don't want to come in and committing them to treatment.

CHAIRMAN OSBORN: I'm going to test the patience of Don, Jim and Eunice for a moment, because we do seem to have a little news pressure here, and David--

VICE CHAIRMAN ROGERS: My apologies. I would like the Commission's permission on something. Tom tells me that already we have had three or four press inquiries about the JAMA piece. On the basis of the conversations we have had, Tom and I have punched that up; we have put in the education and prevention thing. It is a very short statement, but he makes the point that if we don't get this out within the next hour--we will try and write the editorials and we will do those other things, but in essence, it is important. If you will give me and Tom the permission to put together a statement, we can then get it out so that when that story comes, at least there is an immediate response.

COMMISSIONER AHRENS: May I express concern? The center part of this statement, which talks about there are roughly one million people and so forth, and that 10 percent of them so far have developed AIDS--if you are very well-

informed about AIDS, the implications of that may be clear. But for most of the folk in this country, it needs to be much more specific; the numbers have to be played out. I think if we are going to counter this article, which I think can almost obliterate everything we have done if it is captured by the press across the country--and those of us, and June, know that this appears probably in Detroit and so forth--I get it in both newspapers when something like this comes out, and I think, oh, what are we going to do not to counter this.

VICE CHAIRMAN ROGERS: Yes. We can do that.

COMMISSIONER AHRENS: Yes.

COMMISSIONER DESJARLAIS: David, if I could suggest a couple of substantive comments in our responding as a Commission, I think first we should make the point that the HIV epidemic in many parts of the country is just getting started. There is tremendous geographic variation. So that that article looked only at national data and ignores that geographic variation. There are many parts of this country where we are really in the early years of the HIV epidemic rather than in the declining years.

Secondly, obviously, cases will peak at some time and then decline, but all available empirical evidence is that

they will decline to a level that is morally and economically unacceptable to the country as a whole, that they are not going to go down to a very, very small level; rather, they are likely to continue at a level of 40-50,000 cases a year by the most optimistic projections, based on new infections.

CHAIRMAN OSBORN: I particularly vote for the "morally and economically unacceptable" phrase. I like that very much.

COMMISSIONER DALTON: I like that. I don't have any substantive comments. About an hour ago, Diane said if we are going to respond by 5:00, how is it going to happen. By all means, it seems to me that we need to do something and continue doing something.

CHAIRMAN OSBORN: Good. Thank you.

David, we have just commissioned you to take off and go with that. Thank you very much.

VICE CHAIRMAN ROGERS: You can all punch me out afterwards.

CHAIRMAN OSBORN: We will, we will. Thank you.

Jim Allen, then Eunice. And then we should break, and we can continue this to some extent, but I think we should take a break after that.

DR. JIM ALLEN: Don, I don't know much about civil commitment, but I definitely like your level of commitment and applaud that.

COMMISSIONER DESJARLAIS: Thank you.

DR. JIM ALLEN: I've got two questions, and let me preface them by saying that of the studies, the epidemiologic investigations and all that I have read of drug users and their behavior patterns and so on, I get this vague uneasiness. It is a difficult group to work with, a difficult population to study adequately.

We heard statements this morning, for example, of the demonstration projects that I think were started primarily as demonstration projects, and then somebody said, gee, we ought to be studying what we are doing in the demonstrations. It is not clear to me exactly what the history is, but I know that it wasn't a clearly described or focused study at the beginning that set out to evaluate certain hypotheses. A lot of the studies seem to be this very soft type of thing that is difficult to really evaluate--which makes it difficult to know exactly what is going on.

With that as a background, let me ask you two questions. One, can you tell us what has happened in New

York City recently or over the period of the HIV and AIDS epidemics in terms of the usage in the shooting galleries, which are such a widely-described phenomenon of New York City, but not necessarily unique to that; and secondly, among the needle exchange programs that have been written up, where there are sufficient data that have been published and can be looked at--and I realize there is a lot more that is talked about than there is actually published--are you satisfied with the descriptions of what the drug users do when they get the clean needles in the exchange programs?

I have not seen anyone address anything about what level of sharing or what pressures there are to change patterns other than changing the needles and getting a clean one--but does that really affect the using or the sharing behavior?

COMMISSIONER DESJARLAIS: Okay. First, to sort of comment on several things. When those original NIDA demonstration grants started, they were started as demonstration research, and people were encouraged to form explicit testable hypotheses. It was not quite as much shot-gunning, or "let's just go out and do something", as you might have gotten the impression earlier. I mean, at the time those

were started, there were already replicated studies that drug users were already changing their behavior so that there was some basis for making scientific studies as opposed to simply let's go do something.

To draw an analogy, I think that there was as much predictive science in those early NIDA demonstration grants as there was in much of the virology that was being done at the same time. Clearly, people were charting unknown territory, working with very difficult populations, but there really has been consistency in replication in AIDS risk reduction studies.

To give one small example, drug users are much more likely to change their injection behavior than their sexual behavior. That has been found in every study reported in the scientific literature that has looked at both of them. So that there is replication across a lot of these studies.

In terms of the syringe exchange programs, there have been longitudinal follow-ups of people participating in syringe exchange programs as well as self-report. The U.S. data looks very similar to the European data, that participation in syringe exchange is associated with either the same level of drug injection or possibly a lower level. It

is associated with reduced but not eliminated sharing of injection equipment. People report that they try to have a new needle each time they inject, but that does not happen in the majority of cases. But they are less likely to lend their equipment to other people, they are less likely to borrow equipment from other people. So it is clearly a form of risk reduction rather than total risk elimination. Nobody yet has devised a program that will get a new sterile needle and syringe each time somebody is going to inject. But at a population level, people who are participating in these syringe exchanges are clearly lending and borrowing equipment at a reduced frequency compared to what they were doing before they came in or compared to people who are not participating in the syringe exchange.

And again, in terms of ultimate effectiveness, sero-prevalence has stabilized in Amsterdam. In the Swedish study, the rate of new infections among people participating in the syringe exchange is very, very low, under one percent per year. In the Australian studies, where they are doing antibody testing of blood left in the syringes that are coming in, sero-prevalence has stabilized, in the Sydney program.

So nothing definitive, nothing random assignment, but indications of at least reduction in transmission but not elimination.

CHAIRMAN OSBORN: Eunice, Linda, then a break, and then we'll regroup and proceed.

COMMISSIONER DIAZ: Don, I appreciate the information you've give us today. I followed a lot of your research long before I met you on the Commission. I just wanted to ask you kind of a follow-up question from what Harlon started to pry into with you.

In terms of doing research on drug abuse, particularly in the area of the country you come from, usually those research models are set in communities that are generally not of the same ethnic background or cultural background as the investigator. I'd just like to hear from you how you have been able to do the research you have done to involve the community-based research model and what is actually occurring and what Jim just ask you as to what is going on in the shooting galleries, on the streets of New York, with something as prestigious as academic or funded research by NIDA. I haven't heard you address that, and I'd really like you to, because I think it was at the core of our

questioning this morning and very much at the core of what community-based research must be able to do in terms of really cracking this whole drug abuse situation. I'd like to hear from you on that.

COMMISSIONER DESJARLAIS: Yes, there are several strategies. One, Narcotic and Drug Research Incorporated, a nonprofit research institution that I am affiliated with, has had NIDA funding for providing training in drug abuse research for pre- and postdoctoral fellows with a specific emphasis on recruiting Latinos, blacks, African Americans, American Indians, a few Asians, so NIDA has put some specific funds into training minority researchers. That is a difficult process.

In all honesty, a person with the skills to do research in the drug abuse field can probably make considerably more money and gain more prestige doing other types of behavioral or medical research. The history of research in the drug abuse field has been feast or famine--there will be political attention and a lot of money for a few years, and then there will be almost no money at all for a few years. So there are real structural impediments to getting anybody coming into the field, and particularly ethnic minorities who

will have the opportunity to conduct research in a wide variety of behavioral or medical problems can go into fields where the funding is likely to be much more stable, and they are likely to have a faster-track research career. So that it is not simply because there is a lack of qualified people from minority communities who could go into the field of drug abuse research, but the financial and career opportunities are usually greater in other forms of either social science or medical research.

COMMISSIONER DIAZ: My question is slightly different. It deals with how a program or research base like yours incorporates what is going on in the community through some either formal liaison or--

COMMISSIONER DESJARLAIS: Yes, lots of liaison work, lots of meetings to go to; hiring black and Latino members wherever you can find them, training them, seeing them go on to better-paying positions, but deliberately trying to hire them, and then subcontracting out work to community-based organizations. So you sort of try to do a little bit of everything, and it makes your life more complicated than sitting at a lab bench, pouring chemicals from one test tube to another, but it is also part of the

personal rewards of being able to have often very good personal relationships and interactions that you would not have otherwise.

CHAIRMAN OSBORN: Thank you.

Belinda, you get the last shot, and then a break.

COMMISSIONER MASON: I'm going to make this brief and relatively painless.

Don, thank you for being so sensible and telling us something that really mattered and was accessible and wasn't insulting. Thank you for all that. This is maybe one of those things like David proposed to you that you maybe do not want to answer, but consider that you are among friends and just go for it.

If you had to tell us--I figure that eventually, as we all grow together and work together, we will have areas that we trust each other in and sort of leave each other to be the kind of lead on things. And assuming that you are the person amongst us who has obviously the most experience and knowledge and background in the substance abuse are and the area of HIV and drug abuse, what do you think we could do--what I am sitting here thinking that we should do is that we should put in our report that we should have needle exchange

programs. And if you have three or four things that you think we could put in the report, or a couple of things, what are the--and maybe try to overlook the political consequences for just a minute and try to say what really the truth would be if politics weren't involved.

COMMISSIONER DESJARLAIS: That's hard to imagine almost.

COMMISSIONER MASON: Yes, I know.

COMMISSIONER DESJARLAIS: I think the biggest task given this Commission, given political realities and funding realities, will probably be to maintain what we are doing now. NIDA has developed an effective AIDS prevention program that is relatively cost-effective in terms of the number of people reached and the number of people showing at least a reduction in their AIDS risk behavior. The outreach is really quite cost-effective in terms of your ability to start it up very quickly.

We do need to have more drug abuse treatment. That is a longer-term goal. We need to work on that. But we are not going to have an adequate treatment system within the next five or ten years even if we had all the money that we would want.

So I think we need to maintain the national effort that is going on in outreach and not let it fall between the cracks of NIDA as a research institute that doesn't provide services on a continuing basis. And State and local politics, where there will be a lot of other demands on limited Federal dollars, I think really that is going to be the Commission's leverage point, or we need to address that rather than just expect Federal, midlevel staff to address it.

With respect to over-the-counter sales of sterile needles or needle exchange programs, I don't think it is realistic that those are going to be done on a large scale in this country. I don't think it is a good use of our limited resources to push for those on a large scale in this country. There are limited ones that are occurring, and I think we should encourage research being done on them, sort of an open scientific attitude to if a community has started up over-the-counter sales or a syringe exchange program, the Federal Government should be finding out whether it works or not, what the positive benefits are, and if there are negative benefits. But that should be research objective, scientific, and where we need to use our advocacy would be in terms of making sure that the prevention programs going on right now

in this country do not fall into Federal/State limited funding cracks, and a long-term push toward adequate provision of treatment.

CHAIRMAN OSBORN: That's a marvelously concise set of thoughts to work on for a little while, and we certainly aren't done with the topic, but thank you so much for your brilliant input.

I would suggest that we take about a 15-minute break now, reconvene and try and get a little more work done this afternoon. You all surely knew that adjourning at 4:00 was just a nasty tease on our part, that we could not do that, but we will see if we can get a bit of work done after the break and then make some plans for how we proceed tomorrow.

So let's take a break now.

[Recess.]

CHAIRMAN OSBORN: I think we want to be in one sense ambitious but at the same time modest in our objectives for this afternoon.

I am told that there is a lot of press excitement about the JAMA paper, so some of us may end up having a lot of work to do in that regard.

In the meantime, we have two working group discussions that we want to talk about. One of them, we had a chance to deal with to a substantial extent when we met in Los Angeles. My suggestion, unless somebody minds and has a different plan that we should consider, would be that we try and take up what is listed as number two, that is, Federal, State and local responsibilities, now; find out whether there are any surprises in the discussion, and if not, my guess is that we could do that and be in a position to have a consensus in the Commission about that by the close of work today, which I don't think should be after 4:30.

Several of you have asked me, and just to make the answer a little louder, the distance between here and the hotel is about six blocks; the distance from the hotel to the Commission offices is roughly six blocks, and it is a bit of a triangle. So I think a good game plan for those with luggage would be to take a cab to the hotel and walk to the Commission if they like to walk at all. For those who really like to walk, you can do both, and alternatively, you could walk to the hotel and take a cab to the Commission. There are all sorts of good things you could do.

VICE CHAIRMAN ROGERS: Or you can walk to the

Commission and ignore the hotel.

CHAIRMAN OSBORN: And you can walk to the Commission and the heck with the hotel. So every permutation works. But all of it works better if we finish by 4:30. So why don't we start in on the discussion of the working group report number two as listed, the Federal, State and local responsibilities.

Diane, are you ready?

COMMISSIONER AHRENS: Yes. If everybody would take out the draft working group summary report that you had in your packet, there is a new version which we distributed. The only version, I am told, between the old version which you had in your packets and the new version is on page 8, and maybe you can highlight it before we begin the discussion. It is the second sentence on page 8, which reads: "In this way, those who are ultimately responsible," and so forth. That sentence is the only change between the old and the new, and it was inserted, and Don Goldman may wish to share his concerns about that.

What I'd like to suggest, Madam Chair, in addressing this, is that we look at the--I call them the "preliminaries"--it is everything that precedes the recommendation, and if

there are concerns about that, then we move to the recommendations, and then we move to what I call "unfinished business", which are indicated in the recommendations.

So perhaps we could ask if there are any concerns about the preliminaries.

CHAIRMAN OSBORN: In summary, there has been no change from what you had before in the preliminaries, so that would be old concerns, I think, that you brought with you.

Don Goldman.

COMMISSIONER GOLDMAN: I'm sorry--and I know that I have discussed this, and I think there is a section--and where it goes is unimportant, so just let me address it, because there are three places where it could go. It could go in here, it could go in the recommendations, or it also could go in connection with the next report to the President. But I do want to raise the issue in its general format, and this is as good a place or as good a time as any to raise it.

That is, we discuss in here the terms of the partnership, particularly on page 5 of the preliminary item, and we also discuss the requirement of leadership in terms of local, State and Federal responsibility.

I have always believed that when one talks about a

partnership that partnerships do not work effectively unless there is participation by all members of the partnership in it. And participation means providing or utilizing each level's own what I would call discretionary funds or discretionary resources.

One of the things that I heard in our meeting in Los Angeles was the willingness of some local communities to participate in the partnership so long as it was with OPM--other people's money. If there was a Federal grant available, then they were more than happy to participate in the partnership. If there was a State grant available, then they were more than willing to participate in the partnership. The State was happy to participate as long as there was a Federal grant available to do so.

To me, that is not participating as a partner, and I think that we ought to make a statement--and I don't think we have to in this document, and it doesn't necessarily have to be in this document, although I do want to raise it at this level--I think that somewhere, whether it be in this document or whether it be in the next report that we eventually write to the President and Congress, that we are of the view that there has to be a sharing of financial respon-

sibility as well as discretionary resources, and that that is an integral part of being a partner in the process.

COMMISSIONER AHRENS: I think that's a very good point, Don. Once again, if you don't mind, I will put on my "local" hat for a moment and simply share with you in terms of discretionary dollars. In our country, 7 percent of our budget is discretionary, and that has to provide for all the parks and recreational facilities that we provide to the general public out of that 7 percent. I think that is important, but I also think that we've got to be pretty sensitive to where local units are out there with respect to discretionary dollars.

CHAIRMAN OSBORN: Harlon and then Charles.

COMMISSIONER DALTON: Diane, I know your "local" hat. I think I have sat next to you more than anybody in these meetings--maybe someone thinks that you will make me behave--and I think I have really absorbed what you have to say, which is why--and I guess this is an overall kind of comment about the report, though, and may have more to do with the recommendations. I actually thought that you would say more explicitly about those areas in which counties, for example, and cities really couldn't provide the money. I

mean, I saw a lot of sort of things need to happen at the Federal, State and local levels, without specifying whether talking about a partnership in which one partner pays the bill, another partner administers the program, and the third provides the bodies. That is, there may be different kinds of partnerships rather than everybody contributing money. But I guess I just didn't think there was quite the level of specificity about that that I know you and Charlie among others can come up with in thinking about these different areas.

COMMISSIONER AHRENS: Madam Chair, I think what occurred in the process of getting all these folks together is the enormous diversity in this country between States, and even more diversity between local units of government in their ability to do whatever they do. And to come up with any kind of a formula more specific than we were would be really to either over-anticipate the possible or under-anticipate the possible.

So that was sort of our dilemma, and this is awfully generic. I mean, I feel the way you do, Harlon. It is terribly generic. I don't know--Maureen sat through all of this with us, and Charles and Larry--maybe you want to

comment about that.

COMMISSIONER KONIGSBERG: Yes, let me see if I can kind of work through this, and like Diane, I have worn a "local" hat but have also worn a "State" hat, but unlike Diane, I have been the one expressing the need for participation in funding, taking the case to the Diane Ahrens of the world. So it perhaps is a little bit prospective.

For those of us who were at the session in St. Paul, I think we had a number of outstanding examples of strong participation in the issue by local government and also State government. More recently, I was most struck, I think, by the good work that is going on at the New Jersey Department of Health at the State level. There are many outstanding examples at the local level. And partnership and participation does not always mean money. It also means leadership, it means, for example, putting staff at work, just diverting them from something else which has a down side, and we have all done that.

So I think there is a role for State and local government. As a State health official, I have some reservations about our State government getting off-the-hook. The complaining about short dollars, while accurate, there is

some discretion. It is a matter of priorities, I think.

There are areas of the country, clearly, that are so heavily impacted financially that it has got to be a Federal answer with the impact dollars because the Federal Government has the best opportunity to collect the most taxes, is about the crudest way I can kind of put it. All this bleating about the Federal Government is broke is garbage. The Federal Government is not broke because they can literally print money. The States and localities cannot.

Kansas has to have a balanced budget by law, and Diane knows from the local level that that is really true. But within that, there is some discretion. So I think we need to be careful to let anybody off the hook.

I have had the sense that as a whole, I think we have been looking for Federal solutions, and that may be a little bit naive. I think the States do have a role to play, as do the localities, but what the mix is, I'm not sure that we came to any conclusions that day.

The other point that is sort of an editorial point, also on page 5--and I raised this point before, and it is real picky in a way, but it is a relationship thing in another under Federal--it starts off, "Despite a lack of

organized leadership at the Federal level," et cetera. I still would prefer to see the word "overall" rather than "organized". I think there is a world of difference. In some cases, the words "lack of organized" may be true, depending on which agency you are talking about. In other cases, I think that probably that is not a good rap. What is correct is that no one can deny there is not an overall leadership stance on the part of the entire Federal Government, or a national strategy, and there is a slight difference, toward the AIDS issue. We hit that point at several parts.

Now, again, Diane and Larry may not agree, but I think that is still a little picky point that people may dwell on.

CHAIRMAN OSBORN: Larry, you were invited to comment, and then Eunice.

COMMISSIONER KESSLER: Well, you know, partnership and leadership are two words that conjure up a lot of concepts, ideas and so on, and they tend to be buzzwords. But I think that whatever we do, we need to continue to harp on those two themes. I am struck by the buck-passing that occurs at the city, county, State, Federal levels, and also

by the business community, the local CBOs and so on, which we did not in this report stress strongly enough, but we do certainly allude to it over and over, that they've got to be part of this partnership.

One can't help but feel chagrined that they can find--"they" being people who want to be in leadership position--that the four candidates in Texas for Governor can find $50 million for a campaign and then turn around, get elected, and propose spending $40,000 for education around HIV. It is all ass-backwards. And what we've got to do is keep holding their feet to the fire and say to all those levels--and while government isn't funding campaigns, it is the same individuals who are funding government. It is the business corporations and the individuals and the private dollars, the private citizens, et cetera, who get behind candidates and then elect them to run governments, who were supposed to be working on partnerships with other layers of government, and in fact with the citizenry, but yet it all breaks down.

So I think whatever we can do to continue to strengthen those themes, let's say it. And we've probably, from what we have heard, said it as well as we can say it in

this document. We can't put words in people's mouths, and we can't put things on paper that we'd like to see there, but there clearly is a theme that exists on a certain level, and in reality does not exist.

CHAIRMAN OSBORN: Eunice?

COMMISSIONER DIAZ: I'm still having a little bit of difficulty with the recommendation on the creation of the special task force.

CHAIRMAN OSBORN: Just before we get to that, Eunice, I thought Diane's suggestion was good that we follow the "preliminaries", as she calls them, and then go to the recommendations.

COMMISSIONER DIAZ: That's fine.

I wonder if there was just slight omission of foundations which have had an important part and have been players in putting together plans at the local, regional and State levels. I am thinking specifically of Robert Wood Johnson and the particular contribution in Los Angeles. Had it not been for those funds around the country, many communities would not have been able to pull together that package that was arranged with the HRSA demonstration.

I think probably under the section on "Federal",

too, we might recognize that some way to pull resources that address HIV at the local level was through the HRSA demonstration mechanism and that these should be self-continuing beyond the demonstration period. Basically, I would feel better if it acknowledged the role of foundations.

CHAIRMAN OSBORN: I think that's a very good point. Eunice, I'll tell you what. Why don't we acknowledge the value of that suggestion, if nobody objects, and then we'll find a good way to do that rather than trying to write it now.

COMMISSIONER AHRENS: Fine. It was clearly a part of the discussion that we had at the working group, and I think it just got omitted.

CHAIRMAN OSBORN: Yes, that's very helpful.

COMMISSIONER AHRENS: We talk about "private sector groups" and I think maybe we lumped them in with that, and we should pull them out and identify those.

CHAIRMAN OSBORN: Charlie, Don, June.

COMMISSIONER KONIGSBERG: Let me see if I can just tell a little anecdote that maybe has something to do with priorities and how they get set. I just spent about half an hour on the phone on an issue that almost kept me from even coming to the meeting today--and this is not a bad news

issue, this is a good news issue.

This is a Kansas story. There is a very strong children's lobby in Kansas--well-organized, sharp people--and they have succeeded in getting first the House and now probably the Senate--at least the subcommittee--to put an additional $1.5 million into children's programs. I won't go into detail, and for some of you from large States, you will say what a pittance--for Kansas, that is a huge amount. Okay.

Now, last year, through the Governor's leadership, $2.9 billion, which for Kansas is an astronomical amount of money, was put into I'm sure a badly-needed highway program. This $1.5 million, the Governor is threatening to veto, and I am sure there is political posturing and all this kind of thing.

By contrast--and this is a consistent but growing pattern on the part of the children's lobby--by contrast, there is nobody speaking for AIDS in that State on the private side of things, something that, off the record, we are trying to stimulate a little bit. That is a very tricky effort on the part of an appointed official who could go in an instant kind of thing.

So priorities get set in very interesting ways, and

if the State can afford $2.9 billion for highways, it can afford, I would assume, $1.5 million for children, and maybe it could afford $1.5 million to help us get an AIDS care and treatment and early intervention system set up--in fact, it wouldn't take that much to get going in that State.

So I'm not sure exactly how you put that in words, but I think it is possible to have priorities that are a little bit different. David, you've been harping on that since we started about the need to set priorities, and I think it also applies to the State and local level, recognizing that there has got to be some Federal money for heavily-impacted areas.

CHAIRMAN OSBORN: Don?

COMMISSIONER GOLDMAN: I appreciate that your county in Minnesota may only have a limited amount of discretionary dollars. Nonetheless, it could afford something. I have never been on a board of an organization or with a group of people in which even those who were there who were on welfare--I found when they were able or willing to contribute 50 cents or one dollar, if that's all they could afford, they had an investment in the outcome, and they became a more effective member of the partnership in the

process. And it is a different debate when the issue is, gee, I can't afford it, when there is an acknowledgment of the need and a willingness to say, here, I'm spending all that I can spend, and whether or not that's $50,000 or $500,000 or $5 million, but to allow people to get off the hook and say, I can't afford to contribute anything, is really saying that I don't want to be part of the partnership. And that's just my view, and I don't want to harp on it, but that's what I think.

VICE CHAIRMAN ROGERS: Where does it say that?

COMMISSIONER GOLDMAN: It doesn't say that, and again, I'm not saying that it has to be a one-third/one-third/one-third or fifty-fifty, or anything like that. I am saying that everybody part of it ought to be putting something into it, and we ought not to go to any community and have them say to us, "We can't afford anything." It is one thing for them to say "We've done all that we can do, and we have put in all that we can afford." But for them to be able to say, "We can't afford anything," is really, to my way of thinking, them saying, "We don't want to be part of it."

COMMISSIONER KESSLER: I agree with Don, because I think what that does then is it says to the public and to the

policymakers and to the press that there is a climate here, and we are all taking it seriously; we are working together, doing the best we can to address this cold front that is moving in in our area, and all that is behind it.

CHAIRMAN OSBORN: Could I make a suggestion in this context? I think we can agree operationally on the kind of principle that Don is talking about and whether it is put in dollars or in people or in scarce space, in a county building that doesn't have any space or whatever, perhaps somewhere toward the bottom of page 5, either in the second-to-the-last paragraph or the last paragraph, there could be a qualitative statement that says that clearly, the effectiveness of partnerships is greatly enhanced by the material contribution of all members of the partnership. Something of that sort, which is a little bit of "motherhood and apple pie"; on the other hand, it makes the point that you are making in a way that still submits to diversification across the country.

Could we look to some language of that sort, which doesn't beg the question of country dollars versus country personnel versus city, whatever, but nonetheless acknowledges the power of the concept, the need for contribution on the part of all members of the partnership. It may not be what

you wanted, but it would certainly add to the--

COMMISSIONER GOLDMAN: Yes, certainly I would concur with that, and I think it is also fair to say that--which is a corollary to that--and that is that each member of the partnership has a right, it seems to me, to insist that other members of the partnership also share in the enterprise, which is the corollary part to that whole process.

CHAIRMAN OSBORN: Perhaps we can take a look at that last paragraph on page 5 and find a way to capture some of these comments--

COMMISSIONER GOLDMAN: And I did submit to staff immediately following the January meeting in Los Angeles some specific explicit language dealing with that area. And as I said before also--I know Maureen has spoken to me about it--whether or not it is included in this particular document, or whether or not it ends up being included in some other document, I don't have any great preference to it, also. I also know that Congressman Rowland expressed a great concern to me before he left about his concern in that same area, that we don't want to be seen to be putting the entire responsibility at the Federal level.

CHAIRMAN OSBORN: Yes, I think that is a particular-

ly telling point you make, and we are constrained in many of the other things we say since we are a national Commission and responsive to the Federal Government. So this is an important time to say it. And I think maybe we should ask the staff if they can retrieve some of the language you suggested and capture the sense of this discussion without losing the opportunity for individual cases to diversify.

Before we get off the preamble area, the big, long preamble, there is something that has I think become out-of-date, and I hope it doesn't offend you--I guess I am the best one to suggest that it come out, since I'm always the one who says it. That is in the second paragraph of the opening page, where it says, "We were urged to insist that the President and the Congress break the silence of denial and speak out candidly," et cetera. I am happy to say that the President has now publicly scheduled a speech on March 29th on AIDS to a leadership coalition of businesspeople with respect to AIDS; that he has also through his staff sought extensive consultation from me, from other people who are very much involved in the efforts that you would all feel very good about. David has been very much involved in the whole structuring of this.

So that in essence this would be to whip the horse after the fact, if you like. And while it was said to us, and it was germane at the time it was, I would suggest that it is more tactful to omit it at this point. And we will make the same suggestion about any other document that we are considering that might incorporate that feeling.

It certainly would feel good to let out a cry of anguish about how long there has been a silence, but I think as a forward-looking Commission, we may be better off to omit that bit of gratification.

COMMISSIONER ALLEN: Just that one part?

CHAIRMAN OSBORN: Yes, just the quote thing there--I think probably it is easiest to take it all out--having to do with denial. That sentence coming out simply updates it, if you like, in the sense that we have finally gotten to a point where something is going to be said.

David?

VICE CHAIRMAN ROGERS: Everyone has nodded--I think so, haven't they--

CHAIRMAN OSBORN: Yes.

VICE CHAIRMAN ROGERS: Well, then you don't need any more explanation to me. I just think it would look as

though the President, to his credit, has said yes, and he has had fine input. In terms of the speech, if half the things that I have heard that he is going to say get said, we will feel very pleased with it, and I don't think we should put him in a position of looking as though he was reacting to a document of ours when he has already agreed to do this. It would be much better if after his talk, we had a chance to commend him if he does something good. I think the summer sun works better than the north wind in this case.

COMMISSIONER GOLDMAN: And the contrary if he doesn't?

VICE CHAIRMAN ROGERS: Exactly, yes.

CHAIRMAN OSBORN: We have abundant opportunity to continue commenting, so I think that that caveat is always there.

We have had two suggestions for a little bit of reworking of the preamble, and I get the sense that those were the major themes that were--

MS. BYRNES: Could I just recap? Something about the foundations; the language that deals with commitment and partnership, all along the lines of what you have been talking about, Don, and then something that talks about

setting priorities, Dr. Konigsberg, as well, and then the elimination of that sentence.

Have I left anything out? Larry?

COMMISSIONER KESSLER: I probably wasn't clear, but I think we need to amplify the private partnerships, the community-based groups and the private enterprise. And we could actually even use some of the language from the President's report, which says it very well, in terms of the success of those models when they have partnership with government. It is pretty clear.

And we had a real mix of testifiers from various regions where it works well, and some where they have not even bothered.

COMMISSIONER AHRENS: Do we want to accept the page 5 "overall leadership" rather than "organized leadership"? I didn't hear that one. And then we are going to separate out foundations and CBOs and describe that more specifically; on page 5, we are going to talk about material contributions that make up a partnership at all three levels; we are going to omit the silent statement on page 1; we are going to--oh, I have I guess a suggestion; since everyone is making one, I'll throw my two cents' worth in. And I am not sure where

it should be. It could come on page 4, where we describe the county level; probably that's where it should be. It may be assumed in what is said there, but it isn't clear enough, and I think the major role that the National Association of Counties has urged every county to take is to develop a community-based, participatory, strategic plan for addressing AIDS in their county. I think that is a very major issue across the country, whether AIDS is addressed adequately at the local level. I certainly got this sense in Los Angeles, but this has been the thrust of the National Association of Counties, and I think maybe it ought to be said more clearly, right on page 4 somewhere, where we talk about county level.

CHAIRMAN OSBORN: Scott?

COMMISSIONER ALLEN: One of the things that I am struggling to find here and would like to toss it out to the group--I would assume that community-based is also talking about volunteers as well, but also people living with the virus, the partnership and the participation of those who are actually infected being involved in the dialogue and the coordination and being sensitive that we are not just setting policies and seeing if it is okay, but finding what the true needs are. That is something that I would see as helpful in

it.

COMMISSIONER AHRENS: That is clearly identified in terms of the counties plan. We clearly identify that people who are infected participate as another whole across-the-board section of the community in developing that plan, and we get into that.

CHAIRMAN OSBORN: I get the sense that we are in rough agreement about the revisions which have been discussed, and I guess I need the sense of the Commission. I think if we can agree not to try to write precisely, but rather to discuss, we may be able to finish this in a few minutes and have a draft that we can see tomorrow and be done with.

Are you game for that, or the alternative is--

COMMISSIONER AHRENS: Madam Chair, I don't know whether you'd like me to introduce a motion that we accept with the amendments indicated the preliminary part of this report, or do you want to wait until we get through the recommendations?

COMMISSIONER ALLEN: Why don't we wait?

CHAIRMAN OSBORN: Scott--use the mike.

COMMISSIONER ALLEN: I would feel more comfortable waiting to hear how the private sector is articulated.

COMMISSIONER DIAZ: When you mentioned about this county plan, in our State that definitely ties to the State plan. And I know that is one of the recommendations that States should be encouraged to do that, but in the preliminary paragraph about the States, there is no acknowledgment. Some States already have those plans developed, and therefore that last statement you made of a county plan, many times, fits into the State bigger picture. This would be very helpful to mention in terms of the highly-impacted States like California. It is just a little addition to what you said.

CHAIRMAN OSBORN: Okay, fine.

Now, I think even before, the chief concerns about the recommendations on the wording, so that it was well-understood what had been intended by the working group on Recommendation Number 2, and I think that has been reworked, and I think in fact Diane pointed out a sentence that had been subsequently put in to further enhance the meaning that was intended of "implementation", that the kind of task force being discussed was one that would implement and by definition would need to involve those agencies involved in the implementation. So it was intended as kind of an operational recommendation rather than some shift of responsibility.

Is there--Eunice, I promised you the first word on that, and I think that was the one you were talking about, was it not--please, everybody, the reason we are fussing about the mikes even though there aren't too many of us in the room is that the recorder can't do anything unless you are using your microphones.

COMMISSIONER DIAZ: I guess I still have difficulties with this recommendation, and we can take it a step at a time, but recommending that there be a forceful, comprehensive national HIV plan, and then the idea that the Commission is going to say in a statement that the national Commission intends to recommend the policy goals for that national plan, I think is kind of backwards. This kind of recommendation probably, a year from now, in terms of what we have recommended is national policy for this country, might be more in order with what should occur. How could we recommend to the Federal Government to set a major body like this in motion and then solicit input from private--"The task force should include departments in the Federal Government, solicit inputs from State and local governments"--which is very much what we will and should be doing--"and the private sector and CBOs and PWAs", persons living with AIDS.

A lot of that is what I had understood that our Commission would be doing or recommending. One of the things that concerns me is that there is no mention of the ongoing interagency AIDS Task Force that is under Dr. Allen that does a lot of that kind of coordination, albeit it may not be the panacea for all of the ills of AIDS within the system and how to handle this problem globally, but certainly there is already an infrastructure there, and I would like for him to comment right now on some mechanism whereby a lot of the policies discussed in this Commission could be implemented as they are developed with our assistance.

CHAIRMAN OSBORN: Could you just comment on that--and wasn't that the purpose whereby you created that?

DR. JAMES ALLEN: We wrestled with this recommendation when we first saw it in draft a number of weeks ago, and decided, other than my quiet comments that I have made to June and to Maureen and others, which were totally unofficial comments--they were my personal comments. We have found it a very difficult one, speaking for the Department, to respond to because it obviously involves us so intensively. The task force and the Federal coordinating committee that I chair under the authority of Dr. Mason do a fairly good job of

trying to keep track of what the Public Health Service agencies are doing. Beyond that we share information, we try to impart a sense of urgency and try to get involvement. But it really is much more at a staff level and does not--usually, one talks about trickle down or a filtering down--I think we are able to reach the staff level; our problem is getting the filtering up that needs to occur, the focusing of attention right at the very top levels to get the commitment from the assistant secretaries of departments and agencies around the government and of the secretaries, the Cabinet-level people.

I think very clearly that in some way this does need to be done. We do need to get the Secretary of Housing and Urban Development, the Secretary of Transportation, the Attorney General, and Department of Justice and all of the other departments and agencies aware that they have got responsibilities and that they clearly are involved.

I'm not sure what the best way to do it is. This certainly sets out a very specific way that it might be done. My personal preference would be to see something that is not nearly as directive to the President, but that sets the charge for the President, as I think some of the language on

the top of page 8 does--what it is that needs to be done, but does not necessarily specify the mechanism, but gives him a little bit more flexibility in the mechanism to do it.

Very clearly, there is no question in my mind that the intent of what needs to be accomplished is very good and that at my level, at the level of the Assistant Secretary for Health, or even at the Secretary himself, that we don't have the mechanism in place to do it at the present time.

Let me just address one other concern, and it is one that I talked with June about previously, and that is the fact that one of the most important aspects of this, which is the overall responsibility for treatment and the responsibility for setting policies of health care for the Nation is one that has never been taken by any Federal agency; it has not been one that has been taken by the Department of Health and Human Services or its predecessor agency, Health, Education and Welfare, at any time. And that is perhaps a lack that really needs to be examined more carefully by the Commission and addressed by the Commission.

Our only policy-setting, it seems to me, in this area is really indirectly through the economic policies established by the Health Care Financing Administration with

regard to reimbursement mechanisms for Medicaid and Medicare, and even if we were successful at bringing together all of the Departments, I think there is still going to be a very critical component that is not addressed even with this interdepartmental working group.

So I strongly support the intent here. I would urge that maybe we shouldn't lock the President in too much, but that is my personal opinion.

CHAIRMAN OSBORN: I was going to suggest that what Jim has just said is perhaps an operational way to try and proceed. That is to say, my sense from our conversations and from what I know of Secretary Sullivan's concern and so on is that the capital "T.F.", task force, is a problem; that the very great specificity of it is a problem; that the concept probably is not only not a problem, but might be quite a welcome recommendation, in the sense that many people look at the interagency task force that Jim chairs and say, "Oh, well, why do you need anything else?" Well, the answer is because that is in the U.S. Public Health Service, and there are lots of other departments that have Secretaries and whatever involved.

Perhaps we could find a way of saying that a

mechanism at the Secretarial level, at the Cabinet level, be devised to coordinate the many facets of overall societal response to a massive epidemic that will be necessary and avoid the specificity of which Secretary is in charge. I think that is probably another problem, that if you put one Secretary in charge of a bunch of other Secretaries, you may already have an intrinsic problem. And yet we could probably say all of the intent of this and just sort of take away the capital letters and have it be something that everybody does agree on. Clearly, there has to be an implementation arm. Clearly, everybody is running into things where "It is not in my department", "It is not in my purview", and that is a rather systematic problem in the government, but it is certainly a crippling one here sometimes.

And I know from both Jim Allen and Jim Mason that the assumption that all health care is in the U.S. Public Health Service because the word "health" is in both is a source of considerable difficulty.

So it may be that we could de-escalate the language a little bit and actually intensify the effectiveness of the recommendation.

How does that sound to people?

Scott, then Dr. Konigsberg.

COMMISSIONER ALLEN: Well, go ahead and let them travel through that, because I have some questions on content specifically.

CHAIRMAN OSBORN: Okay. Charlie?

COMMISSIONER KONIGSBERG: Real quickly, let me concur very strongly with Jim Allen's comments. I think people fail to realize at the State level as well how health policy issues cut across agency lines. And I think it is terribly important that HCFA, for example, get involved, which is not in the Public Health Service. I mean, it has got to be something within HHS, but it has got to go further than that.

June, I would concur, and I think if it would go down easier with people to be a little less directive, personally as a health person, I would rather see the Secretary of Health and Human Services chair it, but I don't think that is the critical issue here.

CHAIRMAN OSBORN: I think that almost automatically would be the thing that would happen, but if it were done in a way that was more compatible with Cabinet dynamics than I am personally familiar with and worked better, I would be

glad to have it work better.

The substance of what I was suggesting was that we not use the specific phrase "task force", but rather talk about a mechanism which allows for Cabinet-level coordination in the implementation of a national policy.

Don?

COMMISSIONER GOLDMAN: After the references to that task force, there would be a reference to that mechanism.

CHAIRMAN OSBORN: That's exactly right, yes.

Harlon?

COMMISSIONER DALTON: That all makes perfectly good sense to me. I just simply wanted to respond to Eunice's concern about the possible confusion in the language in that paragraph between what we are doing and what this mechanism ought to be doing. And I would just suggest that we drop the last sentence of that paragraph while we are making these changes. Again, it is sort of directive about whom they should talk to and listen to. I think we should certainly indicate they ought to listen to us, but beyond that say nothing.

CHAIRMAN OSBORN: Well, I agree in a certain sense, except that I think what we should try and make clear as we

revise it is that the whole purpose for this recommendation is that many departments will be involved.

COMMISSIONER GOLDMAN: That's the most important part, I think.

CHAIRMAN OSBORN: Yes. So dropping that might lose that emphasis if it is rephrased in a less directive way but nonetheless maintains the concept that this cuts far broader across society than Health and Human Services. That's the central part, and again, in the redrafting perhaps we can capture that.

COMMISSIONER GOLDMAN: I just wanted to ask Mr. Pernick, as another representative from another Cabinet-level position, whether or not--and also, if I recall correctly, you have worked in other Cabinets and in other departments as well, and therefore perhaps have an experience and perception of inter-Cabinet affairs--if you had any views on the subject.

MR. PERNICK: The only suggestion I can counsel right now is practicality. If the President is coming forward with a major address--and it would be billed as a major address on this particular issue--and of course, we should try to get an advance copy and see how it actually is played--we should build upon that and then work downward.

There are mechanisms within the Federal Government, as was pointed out--Jim chairs something--the VA itself is delighted to be finally participating on an interagency basis with other organizations in and out of the government on this issue, but has been quietly doing its own thing anyway. We have never really gotten outside of a Federal domain because we really don't--we deal with people, because we are federally mandated to deal with people.

My other experience in the State Department is really not that germane, except that whenever the President would say something on foreign policy, we would normally salute--you know, we wouldn't have the chutzpa to suggest that maybe he was misstating something, unless it was Secretary of State Kissinger talking about President Nixon.

I really think that rather than going forward and being entirely critical of what may indeed be, at least from some of our perceptions, a lack of national leadership, that we wait at least in this instance two more weeks to see what comes out and what we could use that particular iteration or that speech for.

COMMISSIONER ALLEN: Could this be useful in developing the speech itself?

CHAIRMAN OSBORN: Again, on the matter of practicality, I think it would be overdrawing the knowledge of how things work to suggest that just because we have had extensive input, either that that will be listened to completely or that that would be the total source of input.

So I think we cannot--and probably cannot until the 29th--know what that speech is going to be like. On the other hand, the fact that it is going to happen is a published event, and so we can be comfortable that there will be a speech, and surely, that since it is going to be more than a hello, it is going to have something that bears on this topic. Those are the ranges of certainty, I think.

David?

VICE CHAIRMAN ROGERS: I obviously can't presume to know what the President is going to say, but, Irv, I don't think it will get anywhere near this far. I don't think it is germane to this particular point. I hope he is going to say some very constructive things about the treatment of people, but I don't think it is going to get to this kind of a blueprint, so in that way, I would say we don't need to hold our breath for that talk.

MR. PERNICK: Not from that point necessarily, but

whereas up to now, activists in the area of AIDS, and maybe in other areas, have been able to criticize the Federal Government for not saying anything at the very highest level except when our former President became a former President, now we can at least look to, or possibly look to, leadership at the highest level and use that in many instances, not directly on this point, but certainly in related issues.

COMMISSIONER ALLEN: I think I lost my spot in the rotation.

[Laughter.]

COMMISSIONER ALLEN: But to get back to Number 2, it seems like that is two different recommendations. The first paragraph talks about a comprehensive plan for implementation, but the second one actually says "to develop a forceful, comprehensive national HIV plan". So I'm a little confused about what we're talking about here and need a bit more clarification, because you are actually talking about a plan, not the implementation of one, but a plan, in the second paragraph. So there seems to be--unless I am reading this wrong--the first sentence in the second paragraph talks about developing a "forceful, comprehensive national HIV plan"--not implementation. The first paragraph talks about

implementation of a plan. So that is two different issues right there, and I think that is where I need a point of clarification, because I agree 100 percent about implementation; the concern I have of muddying the waters is the development of the plan in the second paragraph. That's all.

COMMISSIONER AHRENS: If I understood your concern, Scott, I think what we've tried to say here in the revisions we have been through is that it is the job of this Commission to recommend policy; that when we do that, then it is the job of the Federal Government or State or local to take the policy and to develop a plan and to implement the plan.

Now, does that address your concern? That seems logical to me, but maybe I am not hearing something.

COMMISSIONER ALLEN: Well, I really don't think that clarifies it for me. I can understand what you are saying about our task is to suggest public policy, and then for them to put together plan, if you want to state it that way, but it just sounds to me like those are two different issues; that we are asking them to develop a plan and that we will comment on as a public policy matter in the second paragraph. And I may just be reading it wrong, but it just seems like two different issues. Maybe it is only me that has

that difficulty.

CHAIRMAN OSBORN: David?

VICE CHAIRMAN ROGERS: June, let me make a suggestion, since everybody is getting pretty tired. My feeling is the last go-around we blessed Diane and the report except for this Number 2; that on the basis of the discussion we have--I don't know whom I lay this on, whether it is Maureen or whomever--but somebody try and craft just the one again so we could look at it tomorrow. I don't think we can write it or edit it right now, and I know time is growing late, and I think we are running out of effectiveness as a group. I think everybody has run out of gas.

So my suggestion would be assign it to somebody and bring it back tomorrow.

COMMISSIONER ALLEN: It seems like in the first recommendation we let the substance abuse area off the hook again, talking about that. I know you have in your last recommendation that we really didn't have time to deal with the substance abuse prevention, but somewhere it might be helpful to incorporate that into one of the broader public policy areas dealing with substance abuse.

COMMISSIONER AHRENS: You mean under Number 1,

there should be a "5" that talks about substance abuse?

COMMISSIONER ALLEN: Yes.

COMMISSIONER AHRENS: We can certainly look at that.

COMMISSIONER ALLEN: I think they've been off the hook on many occasions when it comes to dealing with this, and I think we need to incorporate them into it.

CHAIRMAN OSBORN: Well, it certainly won't be the only comment we have to make, but I think that is a good suggestion.

All right. I think the sense of the group, from watching nods of one sort or another, is that we might want to call it a day--

COMMISSIONER AHRENS: Madam Chair, before we call it quits, there is a third item which I think we really need to get to, and that is if there is a consensus that we take Number 5 of the recommendations and Number 9 of recommendations and defer them to a discussion tomorrow as to how we are going to deal with Health Care Financing, health care organization and substance abuse, none of which we were able to address in the working group; we just did not have the time or, we felt, the expertise to address it. But I do think those are critical issues, and we would like further

discussion on these. So if we could defer those until tomorrow.

CHAIRMAN OSBORN: I agree very much they are critical issues. I think the questions tomorrow will include where do we go from here, and those are two of the biggest areas going. So if you want to look at this report, you may want to decide enough said; if we are declaring our intention to go further, that may be the way to phrase the question.

With that as an understanding for the moment, let me suggest that we adjourn and reconvene tomorrow at 9:00. In the meantime, I will lead a march on the Commission offices directly for those who feel like walking from here to there.

[Whereupon, at 5:05 p.m., the proceedings were adjourned, to reconvene on Friday, March 16, 1990, at 9:00 a.m.]