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NATIONAL COMMISSION ON AIDS

WORKING GROUP ON SOCIAL/HUMAN ISSUES

BE IT REMEMBERED THAT on the 9th day of July, 1990, at 8:30 a.m., the above-named group came on for discussion before LAURIE S. KOKORUDA, a Certified Shorthand Reporter in and for the State of Texas, at Parkland Memorial Hospital, 5201 Harry Hines Boulevard, City of Dallas, County of Dallas and State of Texas, whereupon the following proceedings were had:

P R O C E E D I N G S

REV. ALLEN: Good morning. I would like to welcome you to the National Commission on AIDS Conference. Before I explain what we're up to as a working group, I thought I would turn this over to the Chair of the National Commission Dr. June Osborn to explain some of the mission as a whole.

DR. OSBORN: Well, I'm here to get a chance to take the benefit of your testimony today just as an interested observer really because the working group that Scott Allen has been chairing is well along in its deliberations and we'll be explaining more about that.

I think it's probably worth emphasizing some background information that you have access to there and letting you know a bit about the Commission itself which was -- began its work in August of last year. We're not a year yet into our two year charge that was -- we were created by an act of Congress in late 1988.

And our very purpose of the Commission was made to be as independent as possible without a presidential commission, but rather the National Commission with five of our voting members

appointed by the Senate, five by the House, two by the President and three Cabinet secretaries as ex officio nonvoting members. And then the Commission in its first meeting was to elect its chairman which turned out to be me and vice chairman Dr. David Rogers.

And we began our business and with Maureen Byrnes as our executive director which been since then looking for ways to be helpful and to meet the mandate given us by that act of Congress which was to try and move the national concensus on the epidemic and to be reactive and proactive in the context of both Congress and the executive so far as national needs are concerned.

It is our hope that unrealistic as it seemed at the beginning perhaps the moving of the national concensus is something that we can achieve in that we are a broadly constituted group both in terms of appointed authority, but also in terms of our makeup.

We have members who provide AIDS expertise but from all manner of direction, so that we have attorneys and public health people, state health officers' positions. Actually, there are minorities in the Commission. And, of course,

you know Reverend Allen's important work, a number of people who have experience with community-based organizations.

And with that as background, we found three different modes of operation: One is Commission hearings which we feel that we must in general hold in Washington because of the nature of the Commission itself. And we ask all of our members to be holding their calendars for those which occur every two months.

Alternatively, we have tried to do some site visits in which we spend essentially full-time trying to see how things are going in areas either because of their regionalism or because of the nature of the problem we're dealing with epitomizes some of the things going on in the epidemic.

And this represents a third format which we chose to try and get as much work as possible out of ourselves over a finite period of time which is to break down into what we've been calling small working groups in which a subset of commissioners under the leadership of one of the members of the Commission, in this case, Reverend Allen, will attack and address a problem that

looks as if it can stand to be addressed at some greater depth than our other two structures would allow. And so, this is the small working group in the human and social issues in the epidemic.

Anyway, it's my pleasure to be able to be here and listen. I'm not a member of the small working group. And I haven't been able to be at all of the meetings; but given that the University of Michigan closes down for the summer, I was able to come and be here. But I will from this point on be an interested listener.

REV. ALLEN: Well, we hope it's more than that, June. And I would hope that we can all be on first name basis here instead of our titles. And before I introduce the Commissioners, I would like to share with you a little bit about why we have asked you to come here.

The working group decided to deal with testing and early intervention. We have had a meeting in Boston, the first meeting dealing with the intervention issues. And we felt that we needed more input and input of your kind of input.

So, we have brought together this meeting and looking at the intervention issues and

through the prism of testing, but also the range of services, what's out there, what's needed, what do you see that's happening in the future and how can we present the issues to Congress.

We have another meeting at the end of this month in September -- excuse me. In Seattle. It's still in July. That's right. And in September, we will provide our final report hopefully to the Commission on the testing and early intervention issues and range of services along with the obstacles to those services.

So, let me introduce the commissioners to you. I'll just go around the table and then we will introduce ourselves and our background.

This is Eunice Diaz, and she is from Southern California, is Adjunct Professor at USC and has worked extensively with the individual organizations out in LA and has worked all over the country. So, the Commissioner Diaz which we will go ahead and start with Eunice.

Larry Kessler is the Executive Director of AIDS Action Council of Boston and has been there for years upon years and is well-versed in the community-based issues.

Harlon Dalton -- Harlon raise your

hand. There you go -- is the Professor of Law at Yale University, has edited the book "AIDS and the Law". Let's see down and around.

Don Goldman is the past president of the Hemophilia Society, National Hemophilia Society and in private law practice in New Jersey.

And Charles Konigsberg is the State Health Director for Kansas and formerly the health director for Boward County in Florida and is well versed in the beginnings of this epidemic and what the public health response has been and is.

So, now, let's go around and just introduce ourselves. Maureen I think we know.

DR. BOWEN: Steve Bowen from the Center for Prevention Services at CDC.

DR. MacLEAN: Bob MacLean at Texas Department of Health, Austin.

MR. WOLF: Hi. I'm Fred Wolf, President of Colorado State Health Department.

DR. DYER: I'm John Dyer from the Offices of Assistant Secretary of Health Regional Office in Dallas.

DR. FRANCIS: I'm Don Francis, CDC Regional AIDS Advisor from San Francisco.

DR. GREEN: I'm Gordon Green with

the Dallas County Health Department.

MR. WILSON: Jane Wilson. I'm the AIDS Prevention Coordinator for the State of New Mexico.

DR. McNULTY: I'm Chris McNulty. I'm in private practice and a physician at the Nelson-Tebedo Clinic here in Dallas.

MR. SCHMIDT: I'm Don Schmidt. I serve on the board in the Policy Committee of the AIDS Action Council in Washington. I live in New Mexico. I'm a long-term survivor living with AIDS.

DR. PINTZ: Fred Pintz. I'm Public Health Service Regional Office here in Dallas,

DR. GUERRA: Fernando Guerra, Director of Health for the San Antonio Health District.

MR. PANZER: Tim Panzer with the Valley AIDS Council in Harlingen.

MR. KELLER: I'm Bob Keller. I'm the Program Director for the STD/HIV Program, Metropolitan Health Department.

DR. LEVINE: I'm Ron Levine. I'm the State Health Director for North Carolina.

DR. MASTERS: Henry Masters,

Medical Director for the AIDS and STD Program in the State of Arkansas and also serving as Assistant Director for our State Tuberculosis Program.

DR. McFARLAND: I'm Louise McFarland, State Epidemiologist from Louisiana. Also private director of the AIDS program.

DR. HARKESS: I'm John Harkess. I'm the Assistant State Epidemiologist in Oklahoma.

DR. ANDERSON: I'm Ron Anderson, President and CEO of Parkland.

DR. LOVE: I'm Nancy Love.

REV. ALLEN: I would like to say that there will be time for comments from the public from one thirty to two o'clock this afternoon, and we want to hear from you on the commission. And we also have formal testimony tomorrow at the Dallas Public Library. And there too, we will have an opportunity for public comments.

Now, let me mention that Nancy is here to help facilitate this meeting. And I'll let Nancy just do her thing here to get us going. So, Nancy.

DR. LOVE: Okay. Thank you. I do mention that the schedule of this meeting is to get as much work out of themselves as possible. I think part of the truth is they scheduled this meeting to get as much work out of you as possible in the short length of time we're going to have this morning.

In looking at the previous testimony, we've come up with several questions. I presume you have them in front of you. They do not. Well, the first one while someone perhaps is looking for those or -- there are five. The first focus I think we need to work with is a working definition of public health.

So, perhaps we could have some views on when we're talking about public health, what this means to different members here. Somebody talk about what the role is, what that encompasses.

DR. McFARLAND: The role of public health in the AIDS epidemic?

DR. LOVE: Uh-huh. Or when you say public health.

DR. McFARLAND: What do we mean by public health?

DR. LOVE: What are we talking

about?

DR. McFARLAND: I think for the most part it means disease prevention. When you think of public health, you think of prevention. Certainly surveillance of disease comes in there.

DR. GREEN: One of the things that our colleagues at the Institute of Medicine did when they wrote that report on the future of public health was to fuzz up a little bit the difference between public health and publicly funded health care.

In an otherwise excellent report, there was allowed to be -- probably as a result of the fact that it was a consensus document, there was allowed to be a certain amount of laxity in the definition of public health. And publicly funded health care became an important component of the book.

I think that has allowed us -- the rest of us and it began long before the book came out too to fall into that assumption that much of what is done by public health agencies is, in fact, publicly funded health care. But the difference is different in terms of mission.

Where public health is directed at

populations, has an emphasis on prevention and seeks to arrive at the common good, publicly funded health care is directed at sick or injured people who have a problem which is identified as a health care -- as a health problem. And the interventions are directed at the individual's problem whether it be AIDS or heart disease or whatever.

One of the things that we've had problems with is coping with the terminology and it's led us to create some administrative structures which don't help because publicly funded health care, there is such tremendous demands for that, that it tends to parasitize public health operations.

DR. FRANCIS: I think it's easy to at least categorize with HIV disease and transmission to look at prevention. The public health responsibilities in prevention dealing with primary prevention; that is, prevention of transmission to uninfected individuals. And secondary prevention; that is, the prevention of disease occurrence in those already infected.

I think those two merge with the concept of early intervention. The aspects of evaluation

that Louise bought up -- I think surveillance is the whole evaluation of the progress, is the counting of cases or counting of infection -- rates of infection are clearly cut that in a different way.

DR. LOVE: All right.

DR. KONIGSBERG: A couple of points and perhaps Dr. Levine from North Carolina will know whether I'm stealing this phrase from the late dean of the School of Public Health, University of North Carolina.

School of Public Health defines public health as the diagnosis and treatment of its patient. And by patient, he meant the community which gets to Dr. Green's point about population based viewpoint which I think is really terribly important.

I don't totally agree that the IOM Report bought that heavily into public health's role in the care of the sick. As a matter of fact, I think there are a number of us who thought they kind of skirted that issue and that may be appropriate.

MS. WILSON: I think though that what I'm hearing is a very small focus on

identification and control of disease. And I think we really have to look at this as a much broader issue.

The identification and control of disease does not talk about prevention, education and those kinds of things that we get into when we talk about chronic diseases, when we talk about noninfectious behavioral diseases and when we talk about AIDS also.

So, I think we have to expand that concept of public health coming from a public health department that does an awful lot of prevention, health promotion kinds of things. I think that that is a much broader area than what I'm hearing some of these comments.

DR. GUERRA: I think all of that and then the additional consideration that public health is as I think we know it is really very much of an outdated and very restricted component within the overall health care system.

And that until we can expand our thinking and get away from that restricted, very preventive orientation and intervention and epidemiological techniques which are tremendously important and will always be very important.

But I think bringing it closer into the mainstream of the community that establishes some very clearly defined linkages with a treatment system and one that encompasses especially within the context of the AIDS epidemic, those extremely important new challeges and opportunities for offering the broad base kinds of interventions and support and counseling and dealing with the myriad of needs that exist in communities, I think it's going to be very difficult for us to catch up.

And I think that the other thing that happens is that it's very difficult to establish the support from a constituency in a community that one needs to affect the kind of change in thinking of the policy makers and elected public officials and those that can hopefully enhance and increase the resources that we need.

DR. LEVINE: I feel although with the boundaries of public health fuzzy. The emphasis has been on prevention and on community-based solutions. The health of populations, premature babies and minorities, whatever.

However, there's a couple of other concepts that these deserve some consideration or

roles. One, of course, is advocacy. Public health can play an organized -- family public health can and should play an important advocacy role even when it is not directly involved in various health programs.

And another is a concept of Dr. Arden Miller; and that is the role of residual guarantor so to speak, that when a service cannot, is not being provided by any other segment of the health care field and yet is essentially public health as a governmentally placed entity throughout, the nation or state has some responsibilities to advocate and even intervene and provide those services.

So, in addition to the traditional community-based population-based responsibilities, I think there are some residual roles for public health.

DR. KONIGSBERG: I have thought for a good while that it's very difficult to separate the treatment or curity of care system from the public health system. That's probably one area where I do differ a bit from the IOM Report.

The lines of prevention and quote treatment are blurring in the private sector and

they're also doing so in the public sector. And I think that's a very important point of discussion in terms of concepts, early intervention where HIV fits into the public health system.

I'd like to mention three major functions of public health that were identified by the IOM Report on the Study of Public Health. The first one being assessment which we'll hear a good bit more about in the September session on public health which includes surveillance in epidemiology.

The second one being policy development. And the third one being assurance. And the assurance as I see it relates not only to intervention of disease, but making sure that care is provided.

And I think the point was made earlier, it does not mean that public health was the one running the clinics or running the system, but somebody has got to take an overall viewpoint about the health of the community and a well-organized health department with good leadership and good vision -- and that's a lot of if's and I understand that -- is often in a good position to do that.

So, it is a much broader function than what is traditionally thought to be public health. Not all of our colleagues would agree that that includes a direct role in provision of medical care. That tends to continue to be a point of debate. What shouldn't be a point of debate is the role of assurance in seeing that it's done.

DR. ANDERSON: As past chairman of the Texas Board of Health, I got involved in the public health issues and understand somewhat the delineation of the responsibilities and who can carry them out.

I think that it's going to be even more blurred, the distinction between public health and primary care particularly as we start seeing early intervention become successful. So, surveillance is surveillance for epidemiological purposes, but it's early intervention.

And that being the case, you'd have good linkages. And I think the key issue here in Dallas is we got to work very closely with our public health department. And I think that's really going to be encumbent of public hospitals around this country to do so.

I visited many places where they are islands unto themselves, and that's something we can't afford in this country at all. I also would say the problem with medicine in general is the practice of preventive medicine and health promotion nearly as much as it should. There is a model out there that community-oriented primary care model where you deal with individual patients in primary care, but also populations where you looking out for information.

And I would suggest that there are ways of looking through them. Another IOM report where perhaps there is a blend of public health and primary care, there is a natural partnership.

I would echo what Dr. Green mentioned though in that many times public health is parasitized. If you compete in the public health budget and the Parkland budget and you got the chronic to deal with and you got the AIDS patient to deal with, not the HIV, asymptomatic patient, always, always the hospital wins in the budget battle.

And I think it's very important that we have dedicated monies in public health and that they not be cannibalized at times because of

needs. It's very, very, very important to get ahead of the power curve; but I think there are models that exist.

And a lot of the problems I see in public health is that cities don't work with counties, don't work with public health hospitals, etc., and state health departments. I mean we're all in our own little territories here. And those days have to go away.

Whether or not it's blurred or not, it probably always will get more blurred. And that means we're just going to have to sit down and find roles and responsibilities so we don't waste the source.

DR. DYER: I think it's possible to think of public health without getting into a division between the provision of health care and management of health care. To think of it as a body of human expertise which starts with excellent clinical medicine which is integrated then with epidemiology and with behavioral science.

And if you integrate all three of those and you look at what goes on particularly with regard to this epidemic, you would have to say

that public health is rarely seen because we have things that are in the scientific medical base now which we are not doing.

We are I think fairly good at the epidemiology insofar as our democratic principles allow us to do so with the rights of the individual in the privates and so on.

But I think we have done rather poorly at integrating some of the behavioral science part of public health particularly with regard to values, particularly with regard to attitudes and with what I would -- I think has been labeled the hierarchy of needs of individuals in the population in integrating what we really already know about that with our practice of medicine and with the epidemiology which we've done so well.

And that it's possible to look at public health in that way and then to come down from that and to think in terms of the function of public health which had been alluded to and which are in the report and to evaluate where we are in this epidemic that way.

DR. PINTZ: I think there's three important contrasts to be aware of. Public health deals with community's medicine, deals with

individuals. Public health operates in community's medicine, typically operates in facilities, in an office, in a hospital.

And I think most importantly though public health reaches out; it seeks. It attempts to identify groups with risk factors using epidemiological methods while medicine operates or medicine waits for individuals to come to it.

The physician waits in an office. The patient comes to the physician. In public health, we go out and find individuals to work with. I think those are three important contrasts to remember.

DR. FRANCIS: I think if I can expand on what Charlie Konigsberg was saying as far as responsibility of public health. Since public health is primarily a government entity at least the organizational structure of it is even though it goes all the way down to the private institutions in terms of preparing a program, that there is a responsibility of public health to really as Bill ~~Fahey~~ Foege would say to mention what is unacceptable. Unacceptable risk, unacceptable treatment, the like.

And that when you're dealing with an

epidemic of an infectious disease which is very traditionally in public health where the Government has a responsibility and where it doesn't and certainly, where it does, where the Government must come forth to take care of disasters, natural disasters, public health disasters, the like is our responsibility in public health even when the current mood of the country is that we don't want government around by and large.

That our responsibility here is to say there are roles for government and if we're going to prevent in a prevention sense the eroding of the can-do American spirit, that we better get out and do something about major problems so that the next problem that comes along, we feel a lot better about ourselves and can conquer that one as hopefully ably as we can this one.

MR. SCHMIDT: I think public health or public health providers are who those many folks who cannot access private health have to rely on. And so, I think there's been a lot of change as it relates to the HIV epidemic in terms of many, many more folks having to try to push those who are public health people into the

treatment arena. We have no choice.

And what we've had to do is spea -- and what's offered in terms of public health service provision from my perspective from community to community and within a state, let alone throughout this country, is very, very different from one place to another.

And I think we're still seeing it evolving in terms of public health role in the treatment arena. And I think we're going to see a whole lot more of it with degrading of America, with the increase of people in this -- with these long-term needs and with the increase of others with long-term needs.

And I think discussing this is real important; but right now, I see why you're -- the Commission -- the concensus statement that came out was fuzzy because I think it's very, very different from town to town.

DR. McFARLAND: Someone earlier mentioned advocacy. And I think for a number of years, we sort of got away from working with the general community. We just went to our clinics. We took care of our babies, our mothers or whatever.

But I think the HIV epidemic has sort of brought advocacy back into play which I think is very good because it involves the total community.

Also one of the things I think we got away from in public health sometimes is the case management idea concept. And I think we've certainly seen that resurgence there with the HIV epidemic.

And for many reasons, this is something that is very good and needs to be looked at again and something that's important in any disease whether it be chronic or acute infection. But I think that we're getting these back into the picture.

DR. GUERRA: I think that there is that fuzziness and perhaps some ambivalence, but I think it's more because of our own discomfort and insecurity.

I think we've settled too much into the roles of administrators and which been maybe too detached from the more clinical type of setting which I think again in the context of the AIDS epidemic is a tremendously important relationship and linkage that must be established.

And we're still very uncomfortable. It's a new role for the traditional public health professionals. And I think that except for those that perhaps are a little more closely integrated into a model of clinical care which I think are really very much the exceptions because the clinical situations that have been a part of traditional public health which been those that one gets very comfortable with whether it's STD or tuberculosis or prenatal care, outpatient, etc.

And there really isn't anything that we have faced previously that is so encompassing of so many other conditions and needs and demands as the AIDS epidemic I think has perhaps introduced us to.

DR. LOVE: Other comments on this?

MR. GOLDMAN: I guess it's more of a question than it is an answer; but from what I'm hearing and listening to, it seems to me that there is a necessary balance and perhaps even tension between the different kind of areas involving dealing with the population on one hand and individuals on the other hand.

And that it is the healthy management of that tension which delineated where the systems

are working well and where the systems are working not because you can't deal with population, you can't do outreach if you don't have facilities available to those whom you're outreaching.

And that has to do with whether or not you're dealing with HIV or mammographies or pap smears or any other kind of things. If you don't have the facilities to care for the people, you can't outreach to them.

On the other hand, if all of your resources are spent dealing with care and you don't have any community-based kinds of prevention and population directed activities, then the system suffers. And there's a healthy tension between the two.

And I don't know whether we can -- whether or not you can necessarily say that one is more important than the other. It's a question of keeping them in a pair of balance. I sort of -- that's what I sort of hear. And I don't know whether that's right.

DR. KONIGSBERG: Let me at the risk of sounding a bit of a pessimistic note, the flip size of the Institute of Medicine Report on the Study of Public Health -- and those who have read

it know what I'm talking about -- described this nation's public health system as being in disarray.

Now, a lot of people in public health are uncomfortable with that phrase. Some of us are perhaps less uncomfortable with it. I think it depends on where you look.

But there was a good deal of discussion in that report about the infrastructure about the public health system and they were concentrating on state and local health departments primarily as opposed to the public hospitals, although I'm sure that a lot of those same comments would apply.

And I think that I made the comment in other settings that the Commission hopefully in the September session needs to look at the public health system the same way they have been looking with a critical but hopeful eye at the medical care system.

There are bright spots in both, and there are difficulties in both. But I think it's been alluded to earlier that many times public health gets left out in the funding issue. And if any of you have tried to be an advocate without a whole lot behind it sometimes in a political

system, that gets to be very difficult.

Many times we're trying to get others to do what we know we truly can't do ourselves. But I think we need to keep in mind that the system itself in this country for public health is just terribly -- it's deemed terribly important by others and needs to be addressed.

DR. LOVE: Want to add anymore to this already broad definition?

MR. KELLER: The only thing I was going to mention and that's sort of in the same line as Mr. Schmidt said was that many times the role in public health especially in something like our community is sort of enforced.

The community as a whole chose to decide that this issue resembled similar to the STD issues and since public health has always played a traditional in not only STD prevention but STD management, that it was much easier for them to assume this role also in HIV management, and it was also more economic for them.

MR. PANZER: Coming from a community-based organization, it was my tendency when I found out that this was going to be one of the topics, kind of do a quick and dirty poll of

people that are providing care or working in prevention.

What is Public Health

And so, I talked with people from different organizations to find out what was their definition of public health. And our local community health center physician said that's us. We provide care to people who -- primary health care to people who can't afford it, who can't afford it in the private sector.

But an official from a local health department said public health is prevention and diagnosis and we stop there. And then we send the person to somebody else for primary care. So, that's where public health stops.

And then health educators told me public health is us. Public health is health promotion and supporting people in the move to make risk reduction, behavior changes and those kinds of things. So, public health has a different definition to different providers.

And so, I talked to people with AIDS that we work with. And to people with AIDS, public health are the people that we turn to when we run out of money.

DR. GUERRA: Well, I think the

other aspect of that is that it essentially has been in the system as I think it was mentioned earlier that it takes care of the poor people, the disenfranchised, those who are not so sophisticated, those who sort of have ownership of whatever problem that affects communities.

And so, public health has had an easy task; and I think it's been easy. And we haven't really had to be so accountable today as we deal with some tremendously complex, social, demographic, economic kinds of conditions that cut across a lot of different sectors of the community.

We have to obviously expand, you know, from what is a very traditional approach and role to a much broader one because we're more closely linked to the mainstream.

MS. WILSON: I think that what Timothy is pointing out is just a good example of how we are looking at how we fit into this whole continuum of services that we provide to people.

And we've sort of gone from the standard what I would call STD model of identifying and controlling the disease, and we've moved on both ends of the spectrum. We have gone towards the

primary care. We've gone towards the referrals and resources that we need to develop in the community to try to get people into the treatment centers.

We've also gone to the left -- what I call the left-hand of the spectrum which is the health promotion, the prevention and that area. So, we've gotten into the health ~~educators.~~ I use my health educators as gorillas and community activists. You know, I try to get them on that end.

And so, I see us sort of moving in both directions, moving our definition in both directions along what is truly a continuum of care for a population. And I think that's where we need to sort of place ourselves.

DR. LOVE: At this time, let me ask you to think for a moment of any issues left out of that definition and then we're going to move on and talk about it more specific.

DR. FRANCIS: I think I'd like to work on that as far as the definition because I think it's very easy to get confused the actual roles necessary and responsibility for those roles and the financing of those roles versus what is

necessary for the individual.

I think it's useful for this group to think about the individual in the community on the public health responsibility and chart out those roles and those necessities and then not get involved until the financing and the responsibilities of those until after. Then each area actually is going to end up different depending on what the setup or the individual structure is.

But it's financial structure versus roles and responsibility of individuals providing the preventive be it primary or secondary prevention not to mention surveillance and the like that's out there.

DR. LOVE: Any other broad areas we want to add to the already broad definition?

DR. PINTZ: Yeah. I think there's one other point is that public health is not -- does not belong to public health professionals, but people can -- the community can be involved in public health and can provide for its own public health.

I think it's important to recognize particularly with HIV disease the important public

health contributions that community groups are making, you know, quite separate and distinct from state, county, local government, other entities or what not.

MS. DIAZ: I think one thing that perhaps has not been emphasized enough is that we are battling years of set patterns of use of different health care systems including the public health system in this country.

I'm thinking of especially minority individuals or individuals from poverty communities or those that perhaps come from other countries. Their traditional use of public health systems has been in times of epidemics, emergencies and disasters, vaccination control, malaria, eradication.

This type of more traditional usage that a population may give to a system really determines what kind of flexibility can be found within that system.

But I would dare say that within this country now, those populations which been exposed to some model of care where there is active integration of prevention, surveillance and good public health practice putting in an environment

of good medical care or at least accessible medical care let's say in terms of what is being provided or should be provided to migrant workers.

Those types of primary care centers that are community-based, the 330 funding, community health centers, and other types of models that are trying to increase access. I'm thinking of a lot of things that are federally funded for individuals who have no other health care resources.

So, my point is that the perception that the population has on not only the individual can begin to push those systems for change. And the kind of models of public health practice, good public health practice may vary around this country depending on the groups that are primarily accessing those systems not only for prevention, education, health promotion, but in addition those essential elements of health care.

DR. LOVE: Any others?

MR. WOLF: I think that it's important to remember that the Government exists for a purpose. Like Don's statement that public health is primarily governmental at least in the

provision of services or was before the onset of the HIV epidemic.

People in a community occasionally recognize that there is a health problem visited upon that community and they have an expectation that a public health department or the public health system per se will if not eliminate that problem will attenuate that problem.

Now, how the public health system goes about responding to that request or demand by the community I think differs greatly from problem to problem. We've heard some examples of chronic disease, some examples of classic infectious disease. But what it does mostly from its perspective of community is to facilitate the attenuation of problems.

In one situation, a public health agency might provide direct services to people. In another, they might outreach to people at greater need for a variety of services. In others, it may motivate or stimulate the provision of services by the private or the public sector.

But I think again it's that concept of community expectation and at least one coordinating agency to facilitate some kind of a

response that we should advocate.

DR. KONIGSBERG: I'd like to pick up on Fred's point. It's called organizing the community. I think our best work in public health is often done through others. It's best done as public private partnerships. And this is not confined to the HIV epidemic.

I think that there's a long tradition of this. And I think what it takes on the part of public health leadership is a quote ownership of an issue. And the ownership sometimes gets confused with control. Sometimes maybe some of us confuse it with that; but to me, it's more of a leadership.

Just, for example, in my state now in addition to the HIV issue, I think our state public health agency is taking a stronger ownership if you will in dealing with the problems of health care to the medically underserved seeing it again as part of an overall public health strategy.

That does not mean that we're going to go out and propose multimillion dollar clinics run directly by public health. That can be -- that's a different role for us in our state but is one

that's not unusual in some other places.

But I think it's leadership and ownership in organizing communities are critical elements in a good public health program.

DR. MASTERS: I think we must realize that in order to carry out and perform our traditional epidemiologic functions and surveillance activities for disease, infectious diseases in particular, the provision of services is extremely important.

In Arkansas, we have very clearly and convincing evidence, for example, that in terms of AIDS case surveillance reporting, that the provision of counseling and testing services in counties is extremely important whether we get an AIDS case reported to us.

We still have a few counties in Arkansas where there are no counseling and testing sites that are run by our public health departments. And in those counties, we don't get the statistical association between whether we get an AIDS case reported and whether we actually have site performance testing services.

With the availability on a limited basis of AZT through our health departments, we have

found another incremental increase in AIDS surveillance case reporting by the physicians now that we have a carrot to attract people and physicians to report cases.

I think it's extremely important that some services be provided in order for us to do a better job at surveillance and some of those traditional aspects of our work.

DR. LOVE: I think I would probably be in error if I did not give public health the last word in working on the definition. Is there somebody from public health who wants the last word before we move on?

I think we need to look now at what public health's role is in the AIDS, HIV epidemic. Since I know we've clarified or mentioned exactly what we mean by public health when we use it.

DR. KONIGSBERG: If I may ask is it a concensus -- you're the facilitator, but is it a concensus that that definition is a broad one? I mean I think that's kind of a critical point. That's why it's vague. Anything that's broad is also vague.

DR. LOVE: That's right.

MR. DALTON: I'm not sure if I agree with that, but I don't know if it's important to go into that.

DR. KONIGSBERG: You don't agree that it's a --

MR. DALTON: I'm not sure there was a definition. I thought it was a very useful exercise.

DR. KONIGSBERG: There wasn't a definition that I saw anybody write down. I agree.

DR. LOVE: There was I think a lot of comments.

MR. DALTON: I don't mean this as a putdown. I thought it was very useful, but I think that, Charlie, you mentioned ownership of the issue. And I'm putting together with Tim Panzer's comments that we see a lot of different actors here owning various issues. And that's probably a good thing. The question is how to put them together and have them operate in cooperation.

But it seems to me that public health is a label that people also want to own because good things flow from that.

As an attorney, I know that if I make an argument in terms of public health as against in terms of individual rights, I'm much more likely to be successful.

So, it's a useful kind of phrase that lots of folks want to lay claim to. And I think people want to own the money, what little money there is. Maybe there's not a lot out there to be owned. But own the money that flows from irrigating to oneself. And I mean this in a descriptive way the label of being the protectors of having the public as one patient, the community itself.

And I didn't hear it so much as a definition as a really quite wonderful and rich discussion of the kinds of interactions and the kinds of actors and the system in their act all of whom claim quite rightly as part of the public health enterprise.

DR. KONIGSBERG: I think we're on the same level.

DR. LEVINE: I think one of the problems is you're trying to combine into the one definition the public health structure and the practice of public health. The public health

family of structure is practicing beyond public health.

In some instances, they're operating in doctor's offices at the wing of the building. Okay. So, that the public health structure has a core responsibility, a mission, but may indeed be providing other types of services. The practice of public health has already been pointed out is undertaken by others besides public health practitioners.

DR. LOVE: We're saying very different things.

DR. McFARLAND: I don't think we should really try to set down a definition of public health. I don't think we could. I think that's not important. I think we look at the aspect of what public health is all about. As it's been said many times, it extends out into the entire medical community.

DR. HARKESS: I think establishing the consensus. I mean what the IOM report defines public health as what we as a society do collectively to insure a society in which people can be healthy.

What we've said here is that those roles

are taken by many different parts of our system. And it's different from what public health -- it's not -- public health departments have only a part of a role in that.

And exactly what role those different sectors take depends on what's going on in the community, what is available to the community. It's a local decision in a lot of ways for -- and it probably varies from over time depending on what the needs, demands, resources available are.

DR. ANDERSON: You know, as I sit and listen being an acute care provider and a provider of large H clinics with a lot of chronic disease and having had public health background to some degree, I think it's not fuzzy, it's schizophrenic.

We're talking about what society should do to protect the public health. We talked about social justice. We talked about public health knowledge, getting equal care. But going to hot spots and dealing with issues that are very important in epidemic. Whereas, we talk about health care of this country provide on equity basis when it's not.

I don't think you can talk about health

care in the context of getting some primary care and forgetting about hospital services, access to health care for secondary interventions after surveillance has been successful. What you have is a system that's broken and public health is trying to pick up a lot of the pieces.

Where there is no public hospital in Texas, AIDS patients don't get care. And in public hospitals where they're so busy -- you saw the lines this morning. People have to stand in line and they're sick.

There are access barriers everywhere, and I don't see how we can separate these things nor should we. I think you have to have a continuum of care and you have to tie them together and you have to be sure the public health works with the predictive care provider, the chronic care provider and the community.

I really think in a way we're talking about public health. And, you know, it's like trying to put a rabbit in an elephant stew. You're not going to do much with a rabbit in elephant stew.

And I think right now the big problems in this country is the access barriers to care.

Once you find these people, -- we said go out and find them -- you get them in the care system.

And here you do that in Dallas. To a degree, that's true. But a lot of times, you can't get people in the care system. And there's nothing worse.

We've seen it in hypertension and stroke prevention and everything else. Cancer surveillance. To go out and survey and find people and you can't get them into the system is cruel. It's a joke.

And right now, I think that what public health -- and we're getting into the business of taking care of patients in their office. They're doing it because the system is failing. They're probably forced into that situation like they were with prenatal care and like they were with teenage pregnancy control. That wasn't fashioned with public health either. You got to do what your community needs.

And I think a lot of this is simply people uncomfortable in this role of being a primary care provider, but there's nobody else to do it. As the gentleman said, they are living with AIDS. What are you going to do? Somebody's

got to take care of the patients.

And I think that we probably are schizophrenic because you're also not dealing with the other side of the equation. Medicine. And if public health is broke in this country, medicine is broke in this country as it deals with indigent care access.

DR. FRANCIS: I agree, Ron, to an extent; but people are dying of many diseases. And they have lousy access all around the world including in the United States unfortunately.

But there's a strong tradition when you've got a transmissible infectious agent that there is a responsibility to the public health. Primary responsibility is to protect the uninfected from getting infected. That is absolutely a strong structure.

When the reality of doing that involves taking care of infected people, we have adjusted in the past to that absolutely fine if it's taking care of an STD or a better model taking care of chronic condition like tuberculosis. There are very strong public health models for that.

Now, that doesn't mean that public health takes cares of all patients or should take

care of all the HIV-infected. The public health responsibility is to circle that individual with whatever is necessary to prevent transmission.

If it's tuberculosis, if it's skin testing of contacts and treating with chemotherapeutic agents, if it's a vaccinatable disease, immunize the individuals around that. Or, if it's a behaviorally-transmitted infection, you immunize with that around the individual. Very strong tradition for that with various tools, but with the same model.

HIV fits into that fine. What you're really saying is the fact is this very wealthy country of ours is running away from all responsibilities be it health care or public health that the system is no longer there to do it.

But let's go back to the primary job of public health for infectious disease, transmission. And let's say everyone else was dying of multiple other things. At least there is a tradition of taking that one because you can do something about it.

DR. ANDERSON: I think the infrastructure has eroded. And I agree with you

both in public health and in the care as well. The infrastructure in the inner city is housing, economic opportunity education in public health.

I guess one of the things we probably need to think of a definition is the public health infrastructure. We had a retreat here recently on what the city and county responsibility was in public health. I was the chair of one subgroup task force.

And one of the biggest things we came up is we need the business community, the political community, the lay community to understand that public health is part of the infrastructure, as much a part of the infrastructure as housing and roads and bridges and prisons and everything else.

We've let it erode just as we let the inner city erode in this country. And now all of a sudden, we have an epidemic to deal with. The public hospital system and the nonprofit hospitals that will work with this epidemic are full now. It's overflowing.

So, we've got to have a public health intervention out there to stop, you know, the epidemic if we possibly can because we're just

getting bathed and we can't handle it. And I agree with you.

It's probably multifaceted, but it seems like we're dealing with public health and you draw a boundary around it with your hands. It's hard for me to draw the boundary around individual patients or population of patients particularly on the issue of behavioral medicines.

And I know June Osborn might speak to this, but most medical schools want to deal with the test tube issues subcellular physiology, things you win the Nobel Prizes for which is fine.

Lack of attention to public health in medschool

Nobody wants to talk about human sexuality. Nobody wants to talk about addictions. Nobody wants to talk about behavioral medicine. I see public health as an answer there and a good laboratory for medical students.

How many medical students are ever exposed, ever exposed to a public health situation during their training? They may go to CDC if they're subselected and they really want to do it, but most of them don't ever see that part of medicine. And I guess that's why I think it's very hard to circumscribe it here like I do with

most specialists.

DR. FRANICS: All I want to do is say that when there's a transmissible infectious agent, you cannot then discuss that as we hear more and more now as how this competes with other problems we have from roads to cardiovascular diseases and subsequent. This one gets worse if you ignore it, much worse and much bigger.

It's a very different situation with a transmissible agent than you have with others. I think we have to be very clear about that. If you ignore transmissible agents, they get worse. If you do something about it, they get better if you have some tools.

DR. GUERRA: If I could just respond to a little bit of that. I guess that if one looks at what happened in the last couple of years with the continued outbreak of measles that has affected some of the large metropolitan areas in ways that are unbelieveable in terms of what is available to prevent that.

And so, I guess that somehow the public health system has not -- something is lacking to still get to the hard-to-reach individuals in communities. That hard-to-reach group of

individuals is out there someplace. And it's part of a much bigger system than what I guess public health is really allowed us to say grace over.

And so, I think that, you know, in our thinking somehow we have to expand from what we've done in public health in a very traditional way in trying to encompass those conditions and see if we can put out some additional kinds of linkages and to those real hard-to-reach, the AIDS epidemic, the minorities, the poor, the disenfranchised, those that are not literate and sophisticated. We need to find them.

DR. McNULTY: A lot of that is being done in this area at least not so much by the public health officials, but by the community-based organizations. Usually, the PWA's themselves have taken responsibility for that --

DR. LOVE: A little louder, please.

DR. McNULTY: Are taking responsibility for prevention of transmission and everything that goes along with it. That puts public health to a great extent on the HIV patients themselves and the community itself because it simply hasn't been answered. The

problem hasn't been answered by the public health officials.

DR. OSBORN: I think, Don, that I might take a little issue with you about whether we know how to contain even infectious diseases in the past public health structure.

I think part of the problem with this discussion is what Ron keeps bringing up and that is that the systems are so broken that we would be better off harping back to things that which been imperfectly or poorly executed.

And I think infectious diseases are a very good example of that because the minute -- and we see it in this epidemic. The minute somebody says the word vaccine, everybody abandons thinking about anything else that has to do with society or public health.

DR. FRANCIS: I agree; I agree.

DR. OSBORN: And the measles epidemic is a particularly good example that I like to quote often now is education is the vaccine for the virus of AIDS. And we don't know how to use it because we have never done very well in infectious diseases unless there was a specific technologically-based intervention.

And I think that we are better off to rephrase the -- and the reason this is fuzzy as has been pointed out is because there's no good working definition in this country to harken back to. We have a gerrymandered system of public health and everything.

And I think we're wiser to be looking at a restructure that happens to involve an infectious agent now; but in a structure that will bear the weight of our elderly, that will bear the weight of chronic disease and other needs for which clearly are tertiary care system is not well situated even in terms of literal structure witness the crowding here or in terms of long-term follow-through and sorts of things that by and large don't involve exceptionally costly hospital beds.

As you know, I'm Dean of the School of Public Health. And at one point, there was some discussion at my university of perhaps subsuming us under an umbrella that would immediately have us cannibalized by the hospital and the medical school. And I offered the president of the university the choice that I said I'd be glad to discuss taking the medical school under the School

of Health.

I think that we've got things backwards and we must be very careful not to go back to old assumptions or else we're wasting the opportunity for this kind of discussion.

DR. FRANCIS: I agree a hundred percent.

DR. KONIGSBERG: To pick up on the measles outbreak, I think it's really impacted in the wilds of the plains of Kansas right now. If you look at our response to measles -- and this gets back to the point about is the public health system in trouble in some cases.

And I think measles is a good example. By 1978, we almost had measles under control. We had an excellent vaccine and we had a public health system that included a strong response from the private sector. I know because my wife was working on that with the private organizations in town working to concert the public health. We didn't get into any arguments over it.

We almost eradicated measles nationally. The response that we see and at least in part to CDC and from the Congress is well, let's throw money into a second shot which implies

vaccine failure when, in fact, it's failure to public health systems by and large.

And Don may or may not agree on that. That didn't stop him from advocating for the second shot money from our legislature you understand because you see other opportunities with it.

But I think we ought to really look at what happened with measles and say well, that may be minor compared to HIV; but it's a symptom. And I think June's got a point there.

DR. OSBORN: You can take another example just to drive that point home. One of the departments in my School of Public Health and one that we've touched on only from time to time in this discussion is the department called Health Behavior and Health Education which no one would think of having in a medical school and yet which is probably the center point of everything that physicians are trying to do.

I think it would be hard to find a lot of physicians who were aware of the data that shows that compliance with the simple prescription for a ten day course of penicillin to prevent rheumatic fever as a two-fold strep throat is less

than fifty percent. Less than fifty percent of the people achieve that ten day interval of therapy.

compliance data & HBHE

And yet, we talk lively about putting people who feel well on an expensive drug over the next indefinite interval of their lives in order to prevent a disease that they haven't been educated well about because we haven't provided counselors.

That's exactly how backwards we have gotten to be. And yet, if you said compliance to most physicians, they would not even understand what you were talking about much less know the literature behind it that suggests that the way things which been going, we have a far worse situation with therapeutics than we do with vaccines.

So, when I say I think we have to accept that fuzziness and look at starting over using the epidemic as an engine to drive us to rethink some of these things, I mean it both medically as well as in terms of public health.

And that distinction I find particularly troublesome. Medicine is what you do if you have failed in health and preventive activities. Then

you have to go into an intervention which is almost invariably far more expensive.

DR. LOVE: Let's begin to focus on the second question which is what is public health's role in the HIV.

DR. PINTZ: Could you clarify that? I mean, you know, we still have the same problem. Are you talking about what is the role of governmental agencies or are you talking about what is the role of, you know, entities or -- because I think there's a difference between public health systems particularly state, county, local systems and public health.

The systems may be in disarray. Public health as a discipline I think is working marvelously. There's not a problem with public health as a discipline. There may be a problem with the way health services are organized and provided. So, I guess the --

DR. LOVE: With reality.

DR. PINTZ: -- point of all that is when we say public health, you know, without distinguishing between the discipline or the organization of services, it leaves me confused. And I need to know what you're -- you know, which

one you want to focus on.

MR. DALTON: I have a slightly different problem. The Commission as a whole is going to spend a couple of days in the not too distant future discussing I think this question.

And so, I'm -- I don't want to tell you how to run this show, but I'm sort of curious about where we're headed and at what point we're going to get to it.

REV. ALLEN: Why don't we share all of the questions?

DR. LOVE: I'm sorry. I thought you had them. The third question is what's the role of a nonconfidential testing. The fourth question is counseling and testing leads to behavior of pre-test and post-test counseling. And then the fifth question is what's early intervention.

MR. SCHMIDT: I would really -- I would like to recommend that this second question we hold until later after some of that other discussion. I think that will help us clarify what public health is and is not doing.

REV. ALLEN: I think my preference would be to move on to what is early intervention

since we've talked about this and then move on to other categories.

DR. LOVE: You want to speak.

DR. FRANCIS: Maybe I can drive the whole system. I view the public health role in the HIV epidemic I think about it as a pyramid of the population as a whole. Population divided into two major groups: A large group of the population really having minimal risk of HIV infection and disease at least at this period of time. The transitional group in the middle of students by and large and then a group whose behavior or medical requirements put them at risk of infection.

And there's various roles of each stage of this, but I think if I can zero up to the top of that pyramid. If you go to the very top, there's a group that's having behaviors or medical genes that put them at risk or occupational needs and then some of those are already infected and some of them are not infected.

If I view early intervention, it's really the very top of that, the group that is already infected and their immediate contacts to prevent transmission.

That is zeroing our public health strategy from this large, huge population that needs information and needs motivation, that needs skills no doubt and for many things of which we can use AIDS as an example, the schools, groups. Clearly, that's moving from one group to the next.

But then when you get up to the top if you had to prioritize, it would be in my concept -- directing your programs to and around HIV-infectious people for primary prevention of transmission to the infected individuals and their at risk contacts be they drug users or sexual contacts.

And for secondary prevention, actually preventing disease occurrence in your HIV-infected people. So, through all your programs of testing that you were going to lead up to, you identified a group of HIV-infected individuals. We've done that to a large extent at least in California. There's an awful lot of infected people who have been identified through both confidential and anonymous testing.

What's happening now is we're failing to take that opportunity in public health both for

primary prevention of preventing transmission to their contacts and for secondary prevention saying well, now that you're infected, hasta luego. We got to go out and do our general population education because we don't have enough funds for that.

And the thought here is with early intervention, you zero your program much more intensively, much more expensively in and around infected individuals, with all concern that the medical aspect of this could eat up all of the preventive aspects which is to me dangerous.

REV. ALLEN: Before we go further, I think it would be helpful of the Commission to hear your definition of early intervention because we're not talking just medical intervention, but the psychosocial.

And so, let's get a clear understanding as to the human and social issues and working group. We are dealing rather intensively with the social structures and intervention point and so forth. So, it's not just medical.

And I was hoping we could extend that to what's out in the community, what do you in public health encounter in not only medical, but also

psychosocially. So, if we could get a definition of what that is, that would be very helpful.

DR. LOVE: Anybody?

DR. FRANCIS: At least in our early intervention programs, we talk about four roles. Medical, the immunologic medical follow-up of individuals; medical intervention when required; behavioral. That is, dealing with the behaviors that will increase transmission or increase disease occurrence in the individual. Psychosocial, the support for the individual including both practical and psychological support so they can adjust to their condition. And then take responsibility for others and themselves.

And then the logistical case management issues of getting the person where they should be at certain times to make sure that they have all of the other pieces all tied together.

You can spread those out in different ways, but at least those are the roles that we describe and they can be done by four people or two people doing various ones or however it may be organized locally with various different skills. And there's different needs early on in infection versus late in the disease. I think those roles

are at least a way to discuss how you organize your program.

DR. BOWEN: Just to expand a bit on what Don said and to give an example -- a practical example about that. CDC and Health Resources and Services Administration which been working on -- for the last year or year and a half, we have been trying to pioneer a community health center based early intervention model in a minority community, high sero prevalence in a minority community.

And there's a couple of things I'd just like to emphasize that would kind of supplement what Don just said. I think the community-based nature of it whereas the people that are running the program have ownership, they are the ones that feel their community is at risk and a threat. And it's the populations that live in their neighborhoods and their own sons and daughters that drives them to succeed at this.

The other is the fact that it appears that both the clinical care and the prevention aspect when put together at one place in a community, both of them function much more effectively and with much more community consensus

that this is what ought to be done.

If care is provided, then counseling and testing and active family involvement in risk reduction works better. If prevention is provided, then more individuals who are at risk either because of their drug use behavior or sexual behavior or their -- those individuals can be identified in a much more efficient manner.

And many of them may not know their own risk. They may not know the risk behavior of their partners. But the clinical care allows a way of providing that preventive medicine and preventive both primary and secondary transmission aspect in a much more -- a way which is acceptable to the community.

Acceptance of counseling and testing is much more easily achieved. And then the clinical care itself is much better done because the case managers and the clinical staff have ongoing responsibilities and ongoing contact with these people who will then understand what is being attempted to be achieved for their own care.

These are a couple of things just to add to what Don's talking about. But it can be achieved very well in minority communities. It

doesn't just have to be in a community such as San Francisco where traditionally this has been organized in and around community organizations that have addressed perhaps well-educated white men.

MR. SCHMIDT: I really like Don's definition of early intervention in terms of it being multicomponent in dealing with the whole person.

I have problems with use of the terms early intervention for anything other than hopefully preventive efforts to keep people from getting this virus.

Once a person is a person with HIV and knows that and has some understanding of their immune function, I have a problem with us as a society talking about treating those people's multiple needs as somehow early.

I really think in terms of a continuum of care for people with HIV. We are along that whole continuum talking about counseling, emotional support, practical support, assistance in activities in daily living for those that need that to stay out of hospitals. And I really think we're talking about client centered care planning

for all people anywhere along the continuum of HIV.

And I would somehow hope that as a community we make it clear that it's -- there's kind of an attitude that if people are sick now, physically sick now, we somehow have to do something. And we kind of are asking if it's as long as people look and feel pretty good, they're not sick now.

And it's important that we do quote unquote early intervention for those who can hold off onset of illness, but it's not quite as important as meeting the needs of those of us who are more sick and having more physical things going on. And I think that's wrong headed in terms of what public health ought to be all about.

MR. DALTON: Don, I hear what you're saying. And I think it's a wonderful way to talk about it and makes a point that you wanted to make. But obviously, you're heading into the face of a term early intervention that's out there with a whole different meaning.

MR. SCHMIDT: Right.

MR. DALTON: Nevertheless, I think

you ought to keep making that point. But I say that because it seems to me that from what I hear, the talk that I hear about early intervention around the country tends to suggest that it is focusing on trying to find those people who are already infected, but more or less well and doing something about them.

And the something usually from what I understand means AZT.

MR. SCHMIDT: If they're lucky.

MR. DALTON: The definition that Dr. Francis gave I liked it too, but I wasn't sure that it squared with what most people mean when they talk about early intervention. I guess that's what I'd like to hear from the people around the table.

For example, the money that is now is beginning to flow for early intervention. Is it for bahvioral follow-up and psychosocial follow-up and dealing with the many logistics problems that people who are infected face or is it the money for drugs?

MR. GOLDMAN: I was just going to basically try to find out whether or not there was some agreement as to where early intervention

begins and ends. And I guess really where Harlon and Don were talking is that early intervention -- is case finding part of early intervention, has community-based education changed behavior as part of early intervention or does early intervention begin when a person is diagnosed as being infected or as Don said it ends when a person is diagnosed as being infected. And I'm not sure.

MS. WILSON: First of all, I think I'd like to say that I haven't seen any money for early intervention yet. But I think that in terms of what we are conceptually doing in New Mexico is looking at providing services to people who we find in our counseling and testing programs who are referred to us from other providers.

This is one of the few diseases where we take an infectious person and ignore them for six to eight years. And I think that's sort of a dangerous thing to do with this disease as any disease. And that's totally against public health models that we have developed over the years.

So, what we're trying to do is take those HIV-positive people and provide them with some services and also to insure that there are public health concerns that are met.

And, for example, I would say that we need to keep them in whatever testing site we have. Whether it's a community-based testing site that's run by us or whether it's one of the health departments.

We need to take those folks and make sure that their TB is taken care of, that their immunizations are updated, that a number of -- that the STD are taken care of, a number of what we call traditional public health concerns are met and that would also include prenatal and family planning.

Then we also offer them really upfront CD4's. And the reason for that is a couple of things. I think, first of all, really to assess where these people are in terms of the spectrum of disease. And to give them good counseling, we need to be able to tell them this is where you are in this disease. It also helps us in our planning process.

If all of the people coming into our counseling and testing programs have CD4 levels of five hundred, I'm going to start getting worried because that has a whole different planning implication than if everybody is coming in with

normal CD4 levels.

And the other component of this is by being able to tell people where they are in the spectrum of disease, I think we will get people coming into counseling and testing programs that are not coming in now because they're saying why should I get tested. You're just going to tell me bad news, and you have nothing to offer.

I think CD4 test is an integral component of the prevention program. It gets a new population coming in for testing. And I think that it will allow us to identify people that we are not now identifying and then look at those people, monitor them every six months with CD4 levels, have them keep coming back to you. You build trust.

People after about the third or fourth visit might be willing to talk to you about partner notification and might be willing to talk to you about some of the bahavioral changes that they are talking about or needing to think about in their life. And they're not going to do that with a single post-test counseling session.

In single post-test counseling session, everybody is in absolute hysteria. And we're just

trying to get them through a crisis. So, that's where I see our program and how it -- what it does to meet the needs.

MR. WOLF: Back to early intervention. I like Don's perspective and appreciate that. What early intervention means to me when I read it and see it and as I hear people talk about it is a fancy word for getting people in to some kind of AZT or prophylactic or preventive treatment.

And if your perspective focuses on AIDS and AIDS mortality, then one could consider that early intervention; but one of the characteristics of public health and all the actors in public health is the focus on primary prevention. And from that perspective, one has to deal with HIV infection.

From the perspective of HIV infection, early intervention means something quite different from secondary prevention which is how early intervention is usually characterized or what's usually meant by that.

Now, how early is early. You know, I've heard people say that the real prevention, the real early intervention for HIV as an epidemic is

to begin with good solid health education in kindergarten to turn people into well functioning old people.

And while I agree that that's a worthy goal, I don't believe that it would also resolve many of the social ills that we currently experience in different segments of our society. And we have to take maybe a more focused approach on HIV.

One of the early interventions that quote unquote public health has implemented was in effect the counseling and testing program. Regardless of whether or not it was implemented for the right or the wrong reason, i.e., the protection of the blood supply, if we look back on counseling and testing be it is as anonymous or confidential, the fact of the matter is that testing programs have empowered many people who perceive themselves at risk by telling them whether or not they were infected at the time of testing and helping to identify that very important group that Don Francis mentioned and empowering them to either access services or make life changes and so on.

Now, that program hasn't worked as well

as most of us would like to see it work and yet it's probably had some major effect.

DR. GUERRA: It's just that as a pediatrician and public health official, I have to maybe approach it a little differently. And I would tend to equate early intervention more with what I would describe as preprimary care in that it has begun very much at the level of the community and sort of developing the thought processes, the decision-making skills, the ideas, the mind set that would then allow those individuals as they go through whatever developmental stages or stages of increasing responsibility as adults and parents, etc., to know whether or not they have certain risk factors in their background or to at least take those appropriate precautions to keep themselves from being infected with the HIV virus.

I think that what is happening and I certainly agree with the roles that Don Francis has described; but I think that's already at a point of intervention and not so much early intervention.

And I see it when we have tried to establish programs that are community-based and

that are within the very high risk sectors of our community with the ethnic minorities, with the social cultural groups of individuals that are disadvantaged.

And when we have testing and counseling sites in our housing projects, nobody comes. And they don't come because they're stigmatized and they don't come -- even though they may recognize that they might have some risk factors, they will not go to them because they will be identified as individuals that think they have AIDS.

And somehow we have to move it back a few steps so that there is that level of comfort within the individuals that would allow them to come forward for the very basic steps of intervention.

MR. PANZER: Just to tie into that, I was going to say that this idea that somehow one facility can bridge the gap between prevention, early intervention and later intervention is a great idea. But does it work especially in rural communities where there is no such large organizations?

And people don't come forward and say I need disease prevention. People don't come out

and say I'm healthy and want to say that way. And so, prevent the diseases that I'm at risk for and then enter the system that way. People enter the system when they're sick especially I think in places that have few resources.

And we've -- in the Rio Grande Valley in South Texas, we've seen exactly this that people feel there's no backup system for them to enter at the prevention stage or at the early intervention stage. And that it is the crisis stage when they enter the system.

And the health care providers in the community also conform to that idea. They see the crisis that they need to respond to. And these warm fuzzy ideas of health promotion and prevention become secondary because of the crises that are entering their door every day.

DR. DYER: And that was the way they were trained in the first place.

MR. PANZER: Right.

DR. MASTERS: I think we need to do a better job of mainstreaming our prevention activities for people who may be at risk for HIV infection.

For example, I think that instead of

sending out groups of people or individuals for specialized sort of interventions that we need to make taking a risk factor assessment to give a risk factor assessment for HIV and other STD's a routine part of clinical care we provide, for example, in our community health centers.

I think that a new patient comes in and registers for a service whether that be hypertension, diabetes or etc., that a part of that registration should include some sort of risk factor assessment and to make that seem more routine rather than something that well, we're singling you out for this special sort of assessment.

I think that's important as a part of early intervention in terms of trying to identify people who may be at risk and who may not realize it.

I think another part of early intervention is trying to make better use of data, data that we obtain. In Arkansas, we analyzed or processed about seventeen thousand specimens for HIV. These are specimens that came from our public clinics throughout our seventy-five counties.

Using that sort of seral prevalence information and these are people that use our clinics. So, it's not a blind and random sort of survey. I think we need to convert that sort of data and information that's more useful at helping us direct our troops in terms of areas of our state where there are unusual or abnormally high increases in prevalence than what we would expect.

We recently did a little analysis and we identified an area as rural in a county that was more than fifty percent rural as having ten times more the expected number of equal cases of infectious diseases expected based on demographic area, race, age group and gender.

And I think we need to make better use of those sort of techniques and try to identify areas that need intensive preventive activities.

DR. McFARLAND: I was hoping that maybe today we can look at the fact that counseling and testing and early education really has not worked thus far as we would like for it to have worked.

I'm not saying it hasn't worked at all; but to come up with something today that we can

look at prevention of the transmission of the virus itself along with taking care of the person after you're infected.

But I think we have to look seriously at the fact that our counseling and testing really has not worked as far as prevention on the infection transmission of this virus. So, I'm hoping that we that are gathered around the table today can look at what can we do to prevent transmission in our states and share information enough to come up with something that we could take home from this along with giving the Commission something.

DR. FRANCIS: I think if we could break this down into pieces. I mean all programs including HIV.

One, you need an overall policy to determine, of course, what generally are you going to do about it. Two, you try to get resources necessary to implement that policy. And then three, you have some sort of a structure necessary to bring that policy and resources down to where you need them.

I think we have by and large failed on all three so far. And so what -- and especially

the resource issue not to mention policy issue. So that you have so little resources to deal with that you couldn't even -- you couldn't even implement the program even if you did make reasonable policies.

Then as a result, you end up with competition. And as a perfect example as our early intervention program in California which has gotten tremendous political support come through legislature, we got lots of extra money budgeted; but the governor continues to veto the money necessary to run it.

And as a result, you get HIV-infected individuals in for behavioral and immunologic monitoring and then the question is are we going to provide AZT. And the clinic said no, we don't have enough money for that. The patients say we need it. And the person who is taking care of the patients at that point, you shift because not only is that your training, but there's an ethical responsibility at that point and so we say absolutely we have to give AZT.

And now we are able to follow one patient for the same cost as we could five. But if you go to Switzerland where I've helped them on

their early intervention program, they don't have that problem.

Why, because their care system takes care of the medical parts of it because this is the standard of care be it a two hundred or five hundred dollar. You get AZT and Aerosol Pentamidine that's a separate issue and boom becomes funded. And you still deal with your psychosocial, your counseling and behavioral counseling and your case management issues as far as the design.

The structure as I see it in the future, I mean if he could -- I think we could sit around this table and relatively rapidly develop what we're really talking about is the continuum of care and the prevention issues at the community level.

And if you really deal with it, you can see I think in the future -- we've had a lot of people testify now we can start early intervention in community care if we wanted to. We have the resources in this country to do it. All we have to do is get those resources to the right place and do it in an organized structure.

But then as you start that, then you

have the difficulty of getting the people tested. Clearly, we're moving into routine testing.

Those people who say gee, are we really talking about routine testing, do we have the ethical ability to do that when we cannot care for the people I think is the way we're going to drive the system. Is that the standard of care is going to be when you come to a physician or medical clinic that is in a voluntary system, you're going to be asked I urge you to get tested if the prevalence is high enough.

I mean clearly, in North Dakota and Montana it may not be. But at least in California, the prevalence of infection coming to any medical clinic is well over one in a thousand for almost any group except for blood donors that have been screened out. And you say that's probably justified routine testing through a voluntary program.

And then you have more people who get tested who end up hopefully in a continuum of care and then you can map out with those individuals where the high rates of infection are. And then you can direct your community-based programs in and around those individuals.

And then your partner notification and couple counseling issues just go by the wayside as is reporting because everyone fits into the system if you've got a continuum care to catch them.

Then you end up with your map of where the infected individuals are in larger numbers and you direct your community-based norm changing programs to those long medicinal programs and then the surveillance of evaluation cut the issue the other way. But the issue clearly is the continuum of care.

Now, whether we have to call it a sexy name like early intervention now to get us through is only because we have not sat down and decided what we want to do and how much money we want to put into an important epidemic like this.

And as long as we do this, we're still going to have to be piecemeal and each organization as represented at least here by government authorities are all going to run away from their responsibility. Why, because they want somebody else to pay for it.

MR. SCHMIDT: Well, and what we do and what we say we do aren't at all necessarily the same thing in terms of barriers to such care,

etc.

Quite frankly, in my state, anybody who walks in the University Hospital who is HIV-positive and has a fairly decent doc and that person will get what they need in terms of at least the medical end of what treatment is all about. They'll be tied into the CBO and they will get the emotional practical support based as needed.

Don't say this real loud because the reality is it's eating up the resources of that state's institution. And the reality is if you live out in the hinterland somewhere, you got to get to Albuquerque to get that care.

But the model, what we should do, what we really are doing in some places and what we're trying to move the system to say we're now doing is finding the resources for -- you got two different things playing.

In some places, you can get real good care if you know how to work the system and work around the system. And everybody are being silent partners in the conspiracy to make the resources we know need to be there, the continuum of care that we know needs to be there to really happen.

And I think we got to get that out on the table and we have real serious health financing issues. And we all know damn well it's not just HIV. What this is role modeling for us is chronic care issues for all kinds of other folks. And I don't know.

DR. LOVE: I see a lot of things people want to mention.

REV. ALLEN: This is to be continued after the break. We have a fifteen minute break and we will continue this.

I would like the Commissioners to come up to the front for a brief discussion on where we would like to see this going. I think it's going very well and it's extremely helpful for us. And so, at least have a brief meeting. We will be back at exactly eleven.

(Short recess.)

REV. ALLEN: The Commissioners have gotten together, had a time together to look at some of the issues we feel are important to us. And Larry brought up something very important to begin our discussion.

DR. LOVE: Right. We're ready.

MR. KESSLER: One of the things

that's occurred to us is that there seems to be a shift going on in the perspective and I sort of liken it to a growing consciousness around any issue that we seem to tackle in this epidemic.

We sort of have to experience it for awhile. We have to go through some trial and error periods before we get a clear idea of what the reality really is.

And I think what would be helpful to us as the Commissioners would be for some people around the table if they can to articulate their notion of early intervention and how it's different now say in 1990, '91 than it was in 1988, '89 based on the experience of where its strong points as well as its failures, does the reality meet the ideal or the fantasy of where we thought early intervention as a concept was going because it seemed to me that there were also -- there was a touch of -- I think Don brought this up in terms of raising the level of prevention in the whole early intervention scheme or schematic here on the process.

And it's things like that I think that are probably or possibly on our mind as well. Other things that you may have thought about in

terms of early intervention that you thought gee, why didn't we think of this in 1988 and '89 when we were developing programs. And in some cases, there are states and counties that still don't have a program, but might learn from the mistakes or errors of an earlier design.

Is that fairly clear to people? Is there anybody that would like to comment on that and add some meat to that sort of --

DR. LOVE: If you'll redefine how you might change it around.

DR. ANDERSON: I think I probably think about '88, '89 and '90 somewhat the same way. I think there's more effective treatment now for people asymptomatic and I think that drives any kind of intervention. If you want to go earlier, you can keep people healthy longer if that's not a cruel hoax as June says and there's nothing there to give them.

Is it malpractice if we don't give people AZT and as John Dyer and I have talked about if they are asymptomatic? And there's no money in the public till for that. So, you're thinking about it now there may be something affecting, but there's still no money. There was

no money in 1988 for the volume of services.

What we have in 1988 and what we have in Texas today though is discrimination. And you got to start looking at what the problems are and why I want to be identified early, why I want to prevent transmission, what's the risk that I'll lose my job, my apartment, my friends, be ostracized.

In Texas at least without antidiscrimination issues, it's still a very high risk circumstance. And even though the treatment may be modestly effective, it still may not be effective enough if I'm a patient or potentially a patient to want to find out.

I think we got to come back to how can we offer a win win situation for someone. And early intervention means a win win situation. And I think not just for the public health perspective of not transmitting the disease. That's certainly a win, but it's got to be a win situation from the potential patient's point of view that what we can offer through human services intervention and through prevention of secondary infections actually is worth it.

In some states in this country, friends,

it's not worth it.

DR. DYER: And for the provider few, I would add because we need to have -- the provider needs to know that if the provider does start an early intervention process and if that process does lead to a situation in which medication is required, that that provider is going to be fairly comfortable that that service is going to be available.

Otherwise, I see providers saying hey, wait a minute. I don't want that in my office records. I don't want to know either that these medications are required because then I have this ethical duty to assist this individual in obtaining those things.

So, it's not just the patient. It's both sides of the fence which been affected by what has changed scientifically in medicine as we have progressed in the epidemic.

MR. KESSLER: Have you found in terms of that ethical question also driving physicians away from care?

DR. DYER: I have no data to say whether it does or it doesn't. I can only suspect that it does because the number of physicians who

are actively engaged in -- someone that suggested that a history such as this ought to be an assessment, ought to be a routine part of primary care.

Well, in our experience even in federally funded community health centers under Section 330 of the Public Health Services Act, we're having one heck of a time getting them to accept their responsibility in doing early intervention because they are saying we can't afford to do all what is required if we do this.

I have no experience with the private sector, but I do have experience inside these federally funded centers. And they are very reluctant to accept this because the obligations that would fall upon early intervention.

DR. KONIGSBERG: I think it might be useful to just re-emphasize the definition of primary and secondary prevention in terms that we're throwing around here because I think it's important.

Primary prevention being the prevention of new infected. Secondary prevention being slowing the progression of the disease process.

And I guess if we're looking at a

transition that occurred over the last period of time, a few months, years, whatever, then I think it's a blending of those two concepts that they're not mutually exclusive, that the infected person may infect another person.

And by bringing that individual into a system, you have an opportunity for primary prevention however difficult that may be. At the same time, the secondary prevention in helping that particular individual.

I have seen -- and not everybody may agree -- a bit of a gap in our response. And I'm just thinking back. This is really based on my own experience. I left a community in Fort Lauderdale where we had within our own health departments mind you the alternate testing sites anonymous, uncertain follow-up, difficulty of plugging them into a system. Then we had the AIDS clinic. AIDS or the money that came from Robert W. Johnson Foundation and HRSA.

And I'm not just here to say that those monies were limited only to the terminal stages, but I think that given the pressures for the very sick and getting them into a continuum of care was very important.

Now what we're seening is some need to bring these kind of concepts together because one hanging out for the other is just not going to get this melting of primary and secondary prevention that I think is really kind of critical here.

DR. McFARLAND: I think certainly to elaborate on what Charles has said and Larry asking what we really think about early intervention and what we think of it. And I mentioned a little while ago that I thought we ought to work on counseling and testing. And is that counseling hasn't really done what we expected it to do.

Certainly, I don't think it hasn't been good. We need something to augment that.

DR. LOVE: We are going to come to that.

DR. McFARLAND: Okay. So, I would just like to say that we look differently at early intervention certainly today than we did three years ago before we had AZT, before we had any kind of preventive.

So, I think we're going to have to get into the fact that certainly the difference in what it was a few years ago.

MR. KELLER: My concern that I would at least like the Commission to be aware of and I'm sure they are is the fact that many times when we describe things like we talk about early intervention and we are able to set some standards or whatever, my concern is that many times dollars are associated with the standards which would -- the standards that are set.

And many times, there's not much flexibility. And what works in one part of the country may not even be close to working in that part of the country.

And it's very difficult when we do access whatever dollars are out there and we consider this as a part of early intervention. And we can even meet those standards, but we may have that covered with certain other dollars and then we have no access to the dollars that we need because so much is set in program.

This is the standard of care. This is what you have to do and here is a whole lot of money to do it. But then there's no flexibility. Say we have a greater need in this area and we can't access those dollars.

So, essentially, a lot of dollars go

wasted or you get services duplicated all over the place. So, there's got to be a large amount of flexiblity depending on where you're at and what your community needs.

MR. PANZER: To answer Larry's question and to confirm some of the things that Dr. Dyer was saying, I think that even in a resource poor area like South Texas, that the private sector and the public sector can both absorb taking care of indigent patient, if they have some of the backup systems like the provision of AZT and those kind of things at an earlier stage.

A lot of these doctors do feel and they have told me directly that they are providing substandard care because the system doesn't back them up. They're more than willing to deliver the care in the office and do those kinds of things, but they can't get T-cell counseling and they can't provide Pentamidine or AZT at the appropriate stage.

So, they do feel either they should not provide the care at all or they're going to do what they can, but they realize it's going to be substandard.

MS. WILSON: I hear a couple of things and one of them is that there's sort of a supposition that there's been an awful lot of what is called early intervention happening in the states. And I think it's time to say the states are not being funded for early intervention.

Having said that, the other side of the coin is I hear a lot of sort of a paralysis of analysis of oh, my God, this is a new program.

And effective counseling and testing disease intervention specialists which been doing this for a long time in New Mexico. And I don't think we're that different.

The disease intervention specialists which been providing a lot of follow-up far beyond the post-test counseling. And it is really what we're wanting to be funded at this point from the states is the actual development of a standard intervention program that we see as extending beyond the post-test counseling session.

And in New Mexico, we've gone from calling it case management to call it early intervention. And sometimes I call it in my fondest dreams, it's the post post-test counseling.

And we've been doing that, but it's not a program and it's not anything that we've been paid for or that we can evaluate. But I would suggest that all counseling and testing programs ought to be doing post post-test counseling for the whole range of CD4 testing, public health concerns like TB and immunizations and then the psychosocial concerns trying to meet those of the clients so we will get new clients in for testing.

DR. FRANCIS: I think one of the greatest quotes of AIDS history was the Administrator of Health as he closed the conference in Montreal when he said are we designing our programs -- if this IS a battle between the virus and the people, are we designing our programs on the side of the virus or are we designing our programs on the side of the people?

And he stood up and said right now, we clearly are on the side of the virus. And the programs that disincentives for testing easiest -- I mean this is a very controversial disease because of its mode of transmission.

And if the Government and the people have any choice, they will deny it and they'll run

away from it. And clearly, we have seen that. So, you put -- you build in the disincentives and then you don't have to deal with it.

And what the dealing is then ultimately I see on early intervention is I see it becomes the standard of care that HIV-infected people should be in long-term follow-up.

And in reality in this country, once you access and get into a program, if you have Pneumocystis and you are sick, you come to your ER here, you will be cared for at a thousand, two thousand dollars a day with no policy decision made whatsoever.

And so, the more chaotic you make it, the later they come in, the more expensive it is. And again, we design it so that the people get the services in the worse possible way, do not get the prevention that's necessary, do it in all sorts of chaos. And we know that infectious diseases love chaos. And so, the system again is designed to maximize the transmission and maximize the cost.

MR. WOLF: You asked about our perceptions of changes from '88 and '89 and I have several. I would characterize that time period at least from my perspective as a time of

enlightenment.

A couple of shifts that I've seen from my perspective is a shift from an emphasis on primary prevention, preventive education to secondary prevention. What's classically called early intervention be that good or be that bad.

I've seen an increased support in all areas and all communities for the need for people who are at risk to be tested. I've seen increased support for the need for more than a one shot counseling visit. The need that Don Francis mentioned of the ongoing care perhaps at a different level.

And I think I'm beginning to hear people talk about a recognition that not all people with HIV infection have the same needs. That this epidemic or the need for services is not as homogenous as we would like to believe it is or as policy makers would like us to arrange it for.

I think that leaves us with a particular challenge at this point in time and that challenge is to put together a picture out of mutli-colored puzzle pieces of what is an effective program at all levels and a model for a standard of care whichever language you want to choose to use that

people can begin to use from a leadership point of view.

Now, one perspective and one difficulty in doing that has been this concept that HIV and AIDS is a quote unquote public health problem. And many agencies or many facilities such as Department of Social Services, Department of Mental Institutions, tertiary care facilities have an easy out. When confronted with HIV services that are necessary, they can say well, it's a public health problem, send them over to the health department as a building.

And yet, early in our discussion, it seemed to me that one concensus was that public health was not just that building that was sitting there. And I think that's a characteristic of the challenge that we're going to face as well. I'll shut up now.

DR. BOWEN: One of the things that I'd just like to make a comment on, our agency does fund counseling and testing. And to a certain extent, some small smatterings if you will of early intervention and follow-up programs.

Our first effort in this arena was to fund California for its first two prevention

follow-up centers. But I just wanted to bring to kind of the Committee's attention the fact that this is a rapidly involving area of public health in many states.

And I think there's two that I'd like to mention. I agree with what Jane Wilson said earlier that we're not doing enough of this and resources aren't there.

But I think South Carolina, for example, was a pioneer in beginning to put state dollars into a county public health nurse, nurse-based follow-up system where the nurses essentially function as case managers and do bahavior reinforcement counseling. And they also attempt out of state funds to provide T4 monitoring and AZT and Pentamidine to everyone who has an immune system or indications for that.

And they're attempting to do this for everyone that comes through both the public health system and anyone who is identified by a private medical practitioner. So, this is one state albeit a relatively prevalence area.

New York, on the other hand, has gone to a different approach which I think is also interesting and not totally adequate, but

certainly has -- is a different approach and one which is an example of a large state attempting to deal with their HIV problem.

One of the things that they've done that's important is to enhance Medicaid reimbursement rates for delivery of ambulatory HIV primary care services. And that includes counseling and testing, initial comprehensive medical exams and evaluation and staging of HIV, ongoing monitoring of HIV infection asymptomatic and counseling to high risk women.

And they've also designated networks of nineteen AIDS designated care hospitals which provide specialized care for persons at all stages of HIV infection.

So, I think there is -- I guess the point to make here is that there is a rapid evolution if you will of different states' and communities' response to taking care of persons with HIV infection.

And there's as many other examples as there are members up here present that could offer their own examples. I just wanted to bring up the fact that there are communities that are attempting to use both local and state and federal

funds to try to put in place some of these systems of follow-up here.

DR. LOVE: Don.

MR. SCHMIDT: Just a couple of comments. I see some tension as it relates to what we call early intervention related to is it prevention or is it treatment. And I see on both the national level and on many states' levels some built-in barriers to keep that tension happening and to allow people to say no, it's our prob -- we want to do it. Let's build our empire or no, it's not our problem. It's the other person's problem.

Here we have CDC and HRSA, you know, prevention care on a national level. And in my state, we've got Department of Health which has said we're prevention. They call Jane's job the AIDS Prevention Service. The Human Services Department supposedly does care and treatment, but only for those Medicaid eligible, etc.

And so, I think we've got some built-in barriers in how we have designed our service provision both on a federal and also on a state level in many places that is a significant barrier to addressing what we call early intervention.

I think another thing we have not talked about yet is, you know, in my experience in doing work in New Mexico and before that in San Francisco, the only monies we've seen come down be it from state, from county, from whatever, are monies that are gotten because of money arguments. If we do this this way now, it'll cost us a lot less than if we don't.

And the whole issue here in terms of what we call early intervention in my mind is keeping people taxpayers not tax burdens for significant periods of time.

And I think in our work with Congress and with our legislators, we have to -- you know, all these things we're talking about this morning are great, but I really think the arguments that make a difference in terms of the dollar flow are dollar arguments.

And I think that it's in our corner. I mean it's clearly smart for us as a society to assist people in meeting their care needs from their earliest -- when they have those earliest needs in their experience with HIV.

Another thing I think we're forgetting is that a lot of the support when we talk about

earlier intervention is emotional support, is practical support, is getting people around the attitude that if anybody sees me take the AZT, I may not keep my job etc., etc.

And who's providing those supports? Are the associations of people living with AIDS and HIV in this country where we have them and the AIDS service organizations? And I'm not seeing us talk about any dollars to support those kind of important infrastructure services.

MS. DIAZ: This past March, we had a meeting of this subgroup or commission in which we heard a CDC representative indicate that there was --

DR. LOVE: You need to speak up.

MS. DIAZ: This past March in one of the earlier committee meetings of this social and human --

REV. ALLEN: That's good enough.

MS. DIAZ: -- group, we heard from an individual, representative from CDC indicate to us that there was a shift in resources from CDC for funds of great portion of the counseling and testing dollars in this country from funding anonymous confidential types of sites to that of

going into the more traditional public health clinics within different health department settings such as STD clinics, etc.

And I wondered if maybe you could shed a little bit of light on that in terms of what the thinking was. And also tell us if there's any results in yet from the evaluation of the combined HRSA CDC service prevention projects that are out there now. I don't know how many there are in the country.

DR. BOWEN: Eunice, the -- in terms of where the expansion of -- and I can only comment on publicly funded now where there's federal or state dollars that they're required to be reported to CDC as a condition of granted award or proper award.

There's been about a three to three and a half fold increase in both what are traditionally called anonymous test sites or alternate test sites or stand alone counseling and testing facilities as well as in the confidential sector.

It is true that we have been trying to increase the public access to counseling and testing in a variety of different venues. And I

think community health centers is an example of the worst place we've done. We think probably five percent of community health centers are currently offering this on even nearly routine basis.

But we're trying to put counseling and testing dollars at least from the federal side into facilities where persons at high risk come in contact with the health care system wherever that may be. And hoping that by doing that, the follow-up care will be improved as well as persons who are at risk can be delivered counseling as well as testing services.

And by that, I mean putting them into drug treatment facilities, STD clinics. And we have done a little bit in the area of putting them in community health centers in high seroprevalence communities.

There has not been a decision by the Government to favor either confidential or anonymous testing. I've had this discussion with Kim Westmoreland on several occasions.

We are expanding and continue to feel that both anonymous and confidential sites need to be supported with public dollars. And different

people are going to feel comfortable going to different kinds of facilities.

I think there are several studies -- and we can go into this in our discussion later -- have shown that men who have sex with men are more likely to want to go to an anonymous test site. So, I feel that we need to preserve that option in states that feel that's important. And we will continue to be able to fund that federally.

In regards to the second half of your question in terms of what the impact of these early intervention programs and really minority community health centers, the three pilots are in Miami, Newark, and in the South Bronx in New York City.

We have found good community acceptance for this. There's been an increase in acceptance rate for counseling and testing these facilities. We found that it takes more staff than we anticipated to follow up the families because we're offering the family not just follow-up of the individual, but feeling that it's very important for family follow-up.

And by that, we mean whatever the person defines as their family, their significant

others. And that that risk reduction for the sex partner and other family members can be easily done in this context of providing care.

We get out of this argument and problems with implementing partner notification because it's in a family context of supportive care and of support for risk reduction.

DR. PINTZ: We've talked for almost thirty minutes about what is early intervention. And I'm still not clear what early intervention is. I think it probably is a meaningless term or else it's a term that has so many meanings that it's meaningless.

I mean some part it appears to be a euphemism for secondary prevention in part. It appears to be jargon in part, a buzz word. Wouldn't we be a lot better off to use a term that has real meaning like primary, secondary, tertiary prevention, education, cure, treatment?

How are we going to -- I mean if we use terms like early intervention that have no real meaning, how will we know what the purpose of these programs are, how will we construct measures of performance that are meaningful, how will we evaluate the output, the outcome of these

programs. I don't know.

It just -- it seems like it will just bring us to a point of frustration and we'll have to throw up our hands and say well, it seems to be working. This is something good. I think we can do better than that.

MS. WILSON: I guess one thing I will say is that I know Oklahoma and New Mexico have come up with some pretty consistent standards as to what early intervention is. John Harkess who is sitting at the table with us and I sort of independently came to a model that looks an awful like each others. So, I think it's possible to come to some agreement in terms of what early intervention is.

The other thing that I would say is I think if we call early intervention strictly a secondary prevention program, we are doing it a great disservice because by offering some services which will incidentally slow the progression of the disease, we are also, as our primary concern, really stopping the transmission of this disease in a primary prevention sense.

So, I see early intervention very much as a primary prevention service. And I felt like

that hadn't been made real clear.

DR. PINTZ: I just wanted to interrupt there for a minute. But what then is the difference between early intervention and primary health services as defined by the World Health Organization particularly as defined at Alamada eleven years ago.

It seems that what is described as early intervention is essentially, is exactly what the World Health organization described as primary health services at Alamada; and that is, basic services provided -- made available and provided in a community that deals with the broad aspects of a disease or of the problems that the community is faced with.

MS. WILSON: I think -- again, I can only answer --

DR. PINTZ: Again, it's -- I mean it seems to me to be a term that's introduced -- that is introduced and that Mr. Dalton talked earlier about using words because of benefits that accrue to those particular words and, you know, but the words very often are confusing and they lead to confusion.

And again, I'd say that we have better

terms to use than early intervention. And I think we ought to use them.

MS. WILSON: I'm willing to call it anything you want.

MR. PANZER: As long as we have it.

MS. WILSON: As long as we have the services and don't drop somebody for six to eight years after they've become infected. And I think that's the critical element.

In New Mexico, we had an argument as to what is primary care and what is public health. As Don said the health department has been very careful to say we're prevention. Somebody else is treatment.

But, you know, we've sort of looked and said okay, the public health departments as they are developed and located in New Mexico can do immune status monitoring and can do psychosocial and can do a number of those kinds of things up to the time when somebody becomes -- has a CD4 count of five hundred.

At that point, we should have during all this time been developing resources, working with community doctors, working with the infectious

disease clinics so that they already which been introduced into the health care system.

But at that point, then I would say that the treatment issues overwhelm the public health issues when somebody has a CD4 level of five hundred. That's what we decided in New Mexico. It may not be appropriate for all states. I think Oklahoma has decided to continue to keep taking care of people, is that right, John, after their CD4 level drops to five hundred?

DR. HARKESS: After talking to Bob Keller, my horizons have been expanded as to what can be done in the public health department. We started in January and created this system basically like -- well, not as sophisticated as what California is doing, but basically offering CD4 count screening for sexually-transmitted diseases, DPD's, family planning services are right there for women who are infected and have post-working relationship with our medical center.

And, in fact, physicians from the ID Service are actually attending the people in the health science center when they encounter someone who is not symptomatic, they're referred to the

health department for a follow-up. Whereas, people who have low counts below five hundred now or people who are ill are referred into the health science's center. It's actually worked fairly well.

Partner notification and our address on a regular basis retrospectively as well as perspectively. And I suspected that the public health department could go further with appropriate personnel.

A nurse practitioner or a physician's assistant under protocol could easily supply or monitor AZT therapy for someone who has not made the decision as to where public health department stops and somebody else takes over obviously depends on what resources are and willful concerns.

MS. WILSON: And I think it could be different for each state and certainly within our own health department Dr. Voorhees, who is a state epidemiologist and has also been an infectious disease doctor, has seen a number of HIV-positive and AIDS patients.

He was arguing for keeping people in the public health system well beyond the five hundred

CD4 levels. The public health departments were the ones that were saying well, let's not do that yet. And I think there's some reality to that.

You know, four years ago, Don and I were fighting to get counseling and testing in all of the health departments. We got that done. And now that's standard of care. And I think that we'll start getting this -- I don't care what you call it. Post post-test counseling is the most logical thing.

But whatever it is that you're doing to that HIV-positive client that is both primary and secondary prevention is going to be a standard of care very probably within a couple of years in the health department. We're implementing this fall.

And I would think that two years down the line everybody's going to say well, what was Jane saying about this CD4 level of five hundred. You know, we're taking care of patients with three hundred.

And I think that's going to happen, but it's a matter of how you implement it in your particular state. We've decided to go a little bit slower and use five hundred as our level for implementation purposes now. Another year, it

will be looked at and evaluated and see what it's done.

DR. GUERRA: I guess I would have to say that if it is going to at sometime in the future be part of a standard of care, that somehow we need to, as I think Fred was suggesting, we really need to come to grips with a definition.

Otherwise, I think that early prevention is still very much part of our magical thinking in public health and it's, I think, more to apease those that speak the loudest and, you know, that have the greatest lobbying take place.

And during the period of '88, '89 to the present, early intervention hasn't worked. It certainly hasn't worked in my community.

When I see the mortality from AIDS go from a ranking of fifth to third and when I see a system that is very closely tied into early or could be tied into early intervention with those trying to qualify for amnesty, for example, and there's nothing available to them when they're recognized as HIV-positive. Even any pretest counseling or post-test counseling or any linkage with resources that exists.

And somehow I think we have to agree on

a basic definition of what we're going to mean by early intervention.

DR. BOWEN: One aspect of this that we haven't mentioned today and it may bring the business of care and prevention back together kind of around on the other side of the circle, if you will, and that's the issue of -- there were at least a couple of papers presented about this in San Francisco about the issue of people that are on antiviral therapy being less infectious.

And Don may want to comment on this. But the concept that people on AZT or other antiviral drugs maybe have a lesser or less virus or semen or be unable to culture virus that the immune status is improved, that anginemia (phonetic) is reduced.

And so, we -- maybe in terms of managing this chronic medical condition, if you will, we maybe have a second benefit of potentially reducing the infectiousness.

And I think this may be something which would then somewhere down in the future can get over the issue of whether treatment is a public health benefit as well as a benefit for the individual. I don't know whether, Don, you want

to say any comment about that.

DR. FRANCIS: I think it's all relative. I think that the behavioral and antiviral effects of early intervention should be easily justifiable at this stage and if there's another tool coming down the way that is more effective -- we're not talking about hundred percent cures.

And I think the nomenclature -- I mean the public health service. What does that mean? Nomenclature is what you decide you want to call it. I don't care what you call it, but I think the issues are you provide the best preventive and primary and secondary prevention to HIV-infected individuals whatever that technology is.

If the salt origin is what we use or if we have the genetic vaccine, that doesn't make any difference. Once we have that structure centered around -- to and around HIV-infected individuals, we'll be able to just add to the pipeline as time goes on.

The problem with that is that some of those pieces in the pipeline, be it EDI or XYZ, down the way are going to be very expensive. And if you have very little money to deal with, the

medical part's our problem.

With early intervention in California, I guarantee you is the erosion of the care, be it psychosocial care or medical care on to the behavioral issues of the individuals, that when you have sick people in your midst and you're underfunded, you will take care of those people appropriately. That is your ethical and moral responsibility as a care provider. And the behavioral stuff falls out first.

And so our responsibility in public health, I think we have to structure it so that that is an essential component that must never be left out no matter what.

MR. GOLDMAN: No. I just want to say I think one way you can get around some of the definitional issues is by making clear that what you're talking about are activities. And you can define them as, I think Don does well, but define them in the sense that they're directed at persons either identified as engaging in behavior at high risk for HIV or, in fact, identified as infected.

Otherwise, you do get into the problem of dealing with, you know, hey, the educational program in kindergarten is part of early

intervention which I think all of us agree is really what we're doing. We're talking about people who have been identified either as being infected with the virus or which been identified and perhaps self-identified as engaging in behavior that -- or which been engaged in behavior which renders them at a high risk for infection.

Then I think it becomes a less problematical definitional issue.

MR. SCHMIDT: I've been hearing a bit about what are we going to do to or for people with HIV. And I think there's a more basic question that we haven't gotten to is for what kind of things, for what kind of services will people who are with HIV or might be with HIV come forward. And I really think that needs to be a little bit of our focus.

The barriers for those who know behaviors in their background have put them at high risk, the barriers to come forward are still a real major issue in that there's now all these arguments about early intervention, staying healthy longer, etc.

And so, those are kind of winning out. And people are coming forward; but they're still

very concerned about will I ever be able to move from this job to any other health plan ever. Well, the answer is probably no.

There's some real arguments we've used in New Mexico in terms of let's keep what we really are calling early intervention here under prevention, and let's have it be anonymous. We do anonymous testing now. How much of the anonymous stuff can we do in terms of care. So, people are not risking their future careers, their potential jobs, etc.

All those barriers to getting people to walk forward and get the kind of care that's best for them and best for our society I think are the things I'd like to really get more deep into as we go through this conversation.

REV. ALLEN: We are going to be spending all day tomorrow talking about barriers, but that's a good point.

MR. SCHMIDT: Well, barriers to services I guess I -- I think that really belongs as a part of this conversation because I think some of the discussions of what we're going to do to or for people with HIV are our next step. Those folks are going to have to be convinced to

come forward and --

DR. FRANCIS: At this level, that's not an issue. I mean all disincentives are there. Man, we can fill our clinics as fast as -- the issue is not getting people in regardless of all the lack of retention that they have. The public health, they're very protected obviously. You don't xerox their charts in public health clinics.

But those issues aren't going to get more important as we actually have a program there. And you want to get everyone in it and then you want to get rid of the denial and disincentives.

But right now, gosh, if we -- I mean if we put these in the newspapers that we had them, it would be deadly because you'd have people knocking their doors down. There's no need to publicize this to get rid of disincentives to get people in the early intervention programs.

DR. McNULTY: In the private sector, it's a major disadvantage.

DR. LOVE: A little louder.

MR. DALTON: What's a major disadvantage?

DR. McNULTY: The possibility of future insurability with the new job. Okay. It's almost a moot point because if someone's positive already, before they get a new insurance policy, they are certainly going to have to take an HIV test.

There are major disadvantages to being known as HIV-positive when just with family, with community interactions, but mostly with jobs. And that's what I see in the private sector.

DR. FRANCIS: Is that any different with at least in the insurance issue with -- I mean that's amazing when I think about back when we would do biopsies and pap smears and such without ever talking to the person. Do you want this in your chart; what is your; job, are you going to change jobs, you know. It's HIV that's driven that.

But if we were just willy-nilly about it before you got right from the chart, positive pap smears. We did a biopsy and you'd say what's this going to do to your health care. We never counseled before. Again, what Eunice is talking about.

DR. McNULTY: It's gotten to a

point where sometimes there are two charts on the same patient in the same office just because of that.

DR. FRANCIS: Bad medical care.

DR. McNULTY: And I fill like ten times more insurance papers verifying someone's health asking for all the past medical records, asking specifically for HIV tests just so someone can get insured.

And it's a zoo because you have on one side the specter of malpractice and on the other side is the patient who thinks you're in his corner and who expects you to be.

DR. FRANCIS: I think the issue of how to integrate to the private sector with these public clinics is terribly important because especially in major gay areas where there is a lot of middle class or two upper class individuals with health care, how do you integrate the early intervention program prevention with the early intervention program medical care.

And what we have done is by and large ignore that to this date, but we're trying to set up some models. And there are some good -- especially the rural -- somebody brought up the

rural issue of dealing with the issues in the rural settings where you've got several docs without many patients. It's really a challenge. It's easier when you have docs in each other's practices. Now AIDS. And you just put a public health person in there partner notification, a couple of counseling psychosocial support, referral and case management.

DR. McNULTY: I think it has to drift down. It can't just be from the public health official to the patient directly because there's too much of a gap between those two.

DR. FRANICS: I agree.

DR. McNULTY: It has just been through some community-based organization.

DR. FRANCIS: You're always going to have to have a community-based organization.

DR. BOWEN: I just wanted to say that this issue of insurance and being able to keep insurance after testing, if the bill that -- the care bill that is in conference committee passes and money is appropriated later, there is a provision in that which will -- may help some in this area and that is the paying of insurance premiums.

Some people -- like Don, I was very struck about what you said at the HRSA AIDS Advisory Committee meeting about this. Even when people have adequate insurance, that keeping that insurance may not be possible. And perhaps some of that may be addressed in this new legislation. And hopefully, that will help in this area that we're talking about.

REV. ALLEN: You're referring to paying COBRA payments which is now thirty-six months or they changed to what?

Dr. BOWEN: It depends on how it comes out of the committee as to how long and what provisions will be in it.

REV. ALLEN: Then you have the difficulty that when COBRA ends and if you're healthy enough and if you're doing early intervention strategy, right when you need it most, it's not there.

DR. LOVE: A little louder, Scott.

REV. ALLEN: Then right when you need it most, it's not there if you're talking about early intervention strategies. So, that's a real flaw.

DR. BOWEN: I'm not going to

address the whole thing. I agree.

DR. FRANCIS: And I think terribly important in this that we're trying to come to grips now is if Care money really comes down is that a lot of this you need somebody called a case manager, called a counselor advisor, whatever you want.

As soon as an individual is HIV-positive, they should be joined into the system. If there in a private doc's office or they come to a public clinic, you need to deal with benefits straight away. You need to deal with what are their needs down the way, enjoin them to a medical group, and then deal with all the needs necessary.

And very importantly for us and really highly necessary is dealing with the needs, having that person not only get the services down to the individual, but report the unmet needs, up the system so that we can put the money where it needs to be.

MR. DALTON: How?

DR. FRANICS: How?

MR. DALTON: Yeah. That's terrible because --

DR. FRANCIS: How to get the money down or how to get the needs reported?

MR. DALTON: Either. How to make the joinder. When you know that somebody is HIV-positive, how do you --

DR. FRANCIS: I think it should be a government responsibility. The person that we call the CADO (phonetic) or a TACO (phonetic) or counselor advisor, or teacher organizer -- and that is part of early intervention -- be available to every HIV-infected person from day go. And that person stays with that person for their lifetime.

MR. DALTON: Mechanically, how do you put those people together?

DR. FRANICS: If that person --

MR. DALTON: If you're a private doc, how does that --

DR. FRANCIS: I think that one you can make and say everyone should be reported and that will join them to the system. I think a much better way if that person provides a service that's valuable to the individual and to the doctor -- the private doctors get eaten up with psychosocial needs and they don't get paid for

it.

So, if the public health is saying prevention is our responsibility and decrease in chaos, then the psychosocial, case management issues are responsibility of government. Every HIV-infected person gets that at a minimum.

If the person is part of a publicly-run clinic, then that's automatic. But if he is in a private doc's office, that person stays with them in their private doc's office.

And then that person gets the service down to the individual and also moves the reporting up. But that -- now, there is an issue though. If you don't have much money, people are going to say you're going to put $6,000,000.00 into case managers in California and we can't even get AZT to our patients.

So again, if your budget has very little money into it, it's all going to go to AZT and you'll hear early intervention is buying AZT. But if you can get the resources up to where you can have a program that you indeed can design with some sort of a reasonable long-term plan, then you can get these people joined and then you end up saving money in the long run we hope.

DR. McNULTY: One of the reasons people come to a private doc's office is to maintain their anonymity. If you take their HIV positivity and blast it up through the system, that's going to defeat the purpose of them being there.

DR. FRANCIS: No, I disagree. I think there are very good ways and proven ways of dealing with that. As a matter of fact, with AIDS patients, it's been done for a long time. But for HIV-infected, you bring the name up to a point; and from then on, it's a number.

DR. DYER: I think the Commission is probably aware that they're meeting in a part of the country that may be somewhat different from California.

And it's important to remember that there are these parts of the country where we have five states who are among the twenty-six with sodomy laws where moving from a private physician's office to the county health clinic which is already overburdened because the Medicaid program in the state only covers -- the economic level is set at twenty-three percent of the federal poverty level.

So, the idea that the health department is going to assume this may be a little bit problematic.

DR. FRANICS: You don't think that California is very broad state and we have exactly the same problems in California as Texas.

DR. DYER: I suspect out in some of the hill countries and so on, it's quite difficult there. But still, the economic base from which you operate and which we operate here and there are people from these states here in the room is so very different and the social pressures and the behaviors.

And I keep coming back to people's personal needs, their hierarchy of needs, and their attitudes and their beliefs. And the importance of integrating that into any public health strategy or strategies that we think we're going to come up with, that is extremely important and custom tailoring that to that part of the country where people are is critical.

DR. McFARLAND: Okay. John really said exactly what I was thinking over here. I'm from Louisiana and we are trying to move towards -- we're one of the states that got an

HIV-planning grant and that committee is moving towards challenging the state legislature for money to move early intervention meaning taking care of early needs for AZT, CD4 counts, and so forth into the public health unit.

And I feel that that's the way we have to go. And I think all of us think that's ideal, but we have to know where there's some money coming from. If the state says they do not have the money, you know, it's just impossible to get this done.

So, we can talk and talk about how wonderful it is and I certainly agree; but without some dollars to do this, I just don't see how it's going to get done. And again, I think it's a real issue that Christopher brought up about getting a person from the private doc into the public health system because of the back or long-term thinking of most people.

And in particular in the southern states where we have all these sodomy laws and so forth, if my name gets into the public health system, what's going to happen to me. So, we've got a lot of education to do in that area.

MR. KESSLER: I think one of the

things we need to say here is the reason we are here is to really hear what some of the local problems are, the nuances, the ethnic barriers, the rural issues, whatever. It's not only the south, but it's also the -- or even in the northeast increasing problem when you get out of the major cities.

And because it's a public meeting and it's all on the record, we should take advantage of this opportunity to get it in the records and to also help us, as we file our report to Congress, etc., because we need to be as broad-based as possible. We really want to tell it as it is, you know, what the barriers really are or what the issues are.

I just wanted to comment also I think on Fred's remarks earlier that whether we're talking about semantics or nomenclature, I think that the truth of the problem that we have when we try to get other agencies out of the public health to respond.

We have confused the situation fairly well by creating new terms because it's a new epidemic rather than use old models that might work out of the fear that we were mainstreaming.

I mean there was a lot of fear of mainstreaming. And I think there probably still is for fear that mainstreaming meant people will fall through the cracks because they're falling through the cracks around other diseases and other social problems anyway.

And we wanted to somehow hold AIDS up or people with AIDS up and make sure they got something. But it is a problem when we are talking with Department of Mental Health or DSS or DYS or all the other agencies that now have a role in the public health of people with AIDS, not only in the care, but in the prevention.

I don't know how we get through this semantics and nomenclature issue to arrive at a consensus around a glossary that everyone uses and buys into, the activist groups as well as the providers and public health and nonpublic health agencies.

It seems like there's almost a need for a national convention of sorts around those kinds of terminologies.

MR. KELLER: I think what's important to realize is that once you establish a public health program especially in an area where

there is a large revolving rural area around you is that what we have found in Nashville is we draw now from Southern Kentucky, Northern Alabama, east and west of the state, but do not access the private systems specifically because they fear the private systems.

There is much more accessibility to discovery in the private system, so they utilized and they really -- I mean it becomes -- it's a snowball effect. Once you become known, then they come in droves.

And our percentages of acceptance of new patients is just -- it's going so fast now that we're really having difficulty just providing the initial care that we wanted to do. That's getting to be a real problem.

DR. FRANCIS: Our experience is the same that you don't want money to pay for private insured, but the reality is they will not access the care any other way because of fear. So, about forty percent of our patients could charge their health care insurance and choose not to.

MR. GOLDMAN: An interesting dialogue between Don and Harlon. I think it's

fair to say that traditionally most people involved in health care planning have recognized the kind of case management system that Don is talking about is not only suitable for HIV infection, but is suitable for every other chronic disease. And we're not talking about either a new or revolutionary concept.

I think it's also important to understand I think what Dr. McNulty is talking about and that is that there are patients within even with the chronic disease system who ought to have the freedom, flexibility, and choice not to become part of the bureaucractic system if they choose to do so. And that avenue must be made available whether or not their reasons are rational or irrational. That is not for us to judge.

So, that the system that mandates a condition for receiving care that you become part of that system is certainly an interesting revolutionary concept that we have to talk about and deal with, but certainly is not appropriate within the time.

The other point is that having those two kinds of systems available I think is also a

useful device perhaps because the extent to which there is a heavy utilization of the private system is probably a pretty good barometer on the inadequacies either in terms of quality or quantity of the availability of the public care system from what I'm told.

And likewise, the extent to which people are seeking the public system and avoiding the private system may be an indication of the quality of the public care system that, in fact, is operating and that it's not so bad to have other systems to coexisting.

DR. FRANCIS: And choice.

MR. GOLDMAN: Right.

DR. LEVINE: I believe that the crucial issue is resource acquisition for comprehensive care for HIV-infected individuals. I mean that's the issue and strategies to accomplish that are what we need to be about.

There are obviously benefits besides the quality of care in terms of reinforcement, risk reduction counseling, so on in the public health, the interruption of the progression of the epidemic. And, of course, if we get proof of reduced transmissibility, that will help a lot in

terms of the strategies that we've accomplished in that enfranchising essentially the HIV-infected individuals for comprehensive and quality care.

The Federal Government has enfranchised people with incident renal disease under Medicare. Many states outside of Medicaid enfranchise many groups. In our state, cancer patients, crippled children, people with sickle cell disease which been enfranchised for financial support of their care outside of the Medicaid system.

North Carolina, we have a successful testing and counseling program. Our state requires every health department to provide free anonymous HIV testing and counseling. We have post-counseling counseling as part of an agressive contact notification program which is run off of an anonymous testing program actually. We're just waiting for resources to add on to that.

What people here which been calling early intervention which combines both public health need and critical ethical care for people with a chronic disease.

DR. McNULTY: To Mr. Keller, you had a good point. One of the reasons that people

will not access the private health care system, the private doctors, is because most private doctors don't know how to treat HIV patients and hold a number of myths about themselves and just terrorize patients therefore.

And, as it turns out, although the private health care system actually has more funds available than the public, the public has more practitioners that are able to actually treat AIDS patients.

MR. KESSLER: Don, I guess in theory, I agree with you about the whole system and the right of the individuals to choose; but I'm wondering what that's going to do to both systems if, in fact, insured patients choose the public health system puts an additional burden on the system that already is lagging behind.

It also feeds the antitax climate in the country because other than Medicaid or Medicare dollars, public dollars; and yet doesn't do anything to make private insurance more affordable because the cost of care in the acute stage often equals now the cost of care in the nonacute stage or in this early intervention.

I mean they're both sort of converging

as equal amounts. And yet, the large number of uninsureds who are going to be coming down with HIV disease, is going to flood the public health system.

MR. GOLDMAN: That's the primary role of Government in terms of its ability to provide the infrastructure and the capability to provide a multidisciplinary comprehensive care team, which will make that system more -- will make that system preferable and therefore more likely to be seen not only by the indigent patients, but also by the patient with insurance because it will have so many other resources that are neither reimbursable nor capable of being covered by the system.

MR. KESSLER: I agree, but I'm not sure Congress agrees or the public agrees. Where are we going with that? You know, is that -- we keep moving off on these diversions which create situations in the public's mind and Congress' mind about why we can't fund any of it or why we can't regulate the insurance industries. Why -- you know, it's all a threat to private enterprise, blah, blah, blah. And we're stuck and we're -- you know, I'm hearing that stuff all around the

table in terms of getting from the model to the reality.

DR. GREEN: I was just going to follow-up on what Chris said. We've got here in Dallas County what twelve, fifteen, maybe twenty physicians that are caring for by far the bulk of most AIDS patients certainly and maybe even HIV-infected patients, too.

And the County Medical Society has between four and five thousand physicians on its rolls. We have initiated some discussions with not only the County Medical Society, but also the local Hispanic and African American Medical Socities to try to enlarge the pool of physicians who are capable, confident, and willing to treat these individuals.

This then, even if we're successful and we're not there yet, but even if we're successful, this still leaves us with the question of how to deal with the case management issue for all these patients that are being taken care of in all these many systems.

MS. WILSON: I think one of the issues here is how to join treatment with prevention, and that's what we're really talking

about. I know in New Mexico, we have used the HIV Services Planning grant, which Dr. McFarland talked about, to really do that, to overlay the treatment network and create a treatment network on top of a prevention network that we've been working on for four years now. I think that's very effective.

That also ties into a number of other things because once you do that, you have got then a combined collaborative group of people both from prevention and treatment that go to the legislature and ask for funds, and it's all in one voice.

We've been very lucky in New Mexico. I don't call it lucky. We've been very skilled in New Mexico.

MR. SCHMIDT: Don't say that. We have too many people moving in already. Texans.

MS. WILSON: Texans. We've been very skilled in New Mexico in getting monies from a legislature that is really very poor. You know, New Mexico is not a rich -- it's not a rich state.

And one of the reasons is that we've got treatment people, we have got the HIV Services

Planning Grant people, we've got Don Schmidt, we've got New Mexico Association of Poeple Living With AIDS, and the ASO's, and the CBO's, and all the other alphabet soup that we could come up with all asking for money for the kinds of things, some public health services kinds of things, some treatment kinds of things, but be able to get money because we've got a package that spans all of this.

And I think that's the key in getting resources. The only question that I would throw up eventually to people is when is the Federal Government going to come in on this. So far, we've put state monies in and in a low incident state, that's okay; but eventually, the Federal Government is going to have to assume some of that responsibility.

DR. PINTZ: Well, I think there is quite a bit of federal money in New Mexico right now. There are a number of community health centers that are funded in New Mexico. There's a homeless -- health care for the homeless program funded in Albuquerque.

The point of these programs is the provision of primary health services. That's the

comprehensive services, comprehensive health services with continuity.

MS. WILSON: But they are not continuous with the public health services.

DR. PINTZ: Oh, indeed, they are. There's also a grant to the state government of New Mexico to accomplish that very thing.

MR. SCHMIDT: It ain't worked yet.

DR. KONIGSBERG: I'd like to try to put this discussion of funding in a little bit of a perspective from the real world of Kansas a little bit. I'm going to forget Fort Lauderdale. And it may relate a little bit to the New Mexico situation, a low incidence state, largely rural.

Let me tell you the reality of the funding situation. There's a tendency to say just send money. And I love to say that and Steve Bowen knows that I love to do that and HHS does, too. It's not quite that simple.

You have to have flexibility with the funds. Now, there have been some changes in how the Federal Government directs funds. I think I frankly was quite pleasantly surprised when we were allowed to use a little bit of our CDC regular AIDS grant go into a case management

project. That wouldn't have occurred a few years ago, but that's just a start.

DR. BOWEN: We do our best, Charles.

DR. KONIGSBERG: Yeah, I know; but this is part of this transition. But the reality goes further than that. So, it won't look like I'm, quote, blaming CDC because I'm not blaming anybody. It's just reality.

I'm in a public health system in Kansas that has whole a lot of the past history. It has a history of ninety-four independent county health departments -- they're not units; they're departments -- serving one hundred and four out of one hundred in our five counties. I'm dealing with a system that has the funding reality based on past history, but is strategic plan we've developed for AIDS and HIV isn't married with the funding yet, although obviously, we'd like to do it.

We're dealing with a lack of advocacy system. It's interesting and one of the big differences I'm hearing between New Mexico and Kansas is that you've got people out there that are pushing this and that you've been able to --

you've got allies.

We have had in our state literally through our agency try to, quote, organize the state which is a damn dangerous thing to do for a public official.

As a matter of fact, the other day when I heard that there's a legislative committee now spinning off from the Kansas State networking project, my first response to our AIDS director was now it's time to shove the baby out. And you all know why we say that, so as we're getting to where we want to go.

But the reality is we've got to have the flexibility. We've got fifty-one counseling and testing sites still based on that old opinion outmoded alternate testing site that was based on trying to protect the blood supply in ninety-four of those counties health departments when we don't -- we can't support that many.

If we could take the money that we had state and federal -- and we have some state money -- and redesign it along the lines that we're talking about here, we could do a lot more. It wouldn't be enough, but -- and then we got the little AZT program that the Feds give us kind of

hanging out. And then like a lot of states, Medicaid and the Social Services System sits outside from the public health system.

The reality is yeah, we need more money; but we also need the flexibility to spend it in a creative way that'll do some good.

DR. FRANCIS: It's interesting that we spend so much time discussing the money when I think again the consensus here would be that we could design programs that would be logical and ethical and cost savings in the long run.

And the interesting thing is that we all paid for this. No matter how you do this in health care costs, you take the total people and divide it by your total health care cost, you come up with your $2,500.00 a year, what it costs us in this country, and yet, we're all -- everyone's pulling away. The Feds don't want to spend because if they're too far ahead and the states won't match, etc., etc.

It seems like that you result there again in designing a program that favors the virus, one that does not meet the standards of medical care I don't think, one that does not meet the standard of public health care for a virus

that has a mortality like this. And if they don't meet the standards of care, we call that malpractice.

And yet, we sit down and instead of trying to design a program that would work and then say, Feds, you can put in this part and state will put in this part and local, you can put in this part and go ahead and do it, you continue -- everyone's trying to back away from their individual responsibility of paying any of it. And so, it does not occur.

MR. SCHMIDT: I'd like to go back to Larry Kessler's comments early in terms of geographic issues and in terms of what happens where because I think that's really crucial. I think any good case manager dealing with people with HIV right now would do what I used to do as a case manager in menthal health and really look for the geographic cures.

Our standards of care are localized in communities and states to some extent; and they're very, very different. New Mexico's system is really the San Francisco model of try to overlay that on a more rural place.

One of the things we found is we are

clearly no longer a low incidence area. And there's a lot of look at the Kansas' and New Mexico's as low incidence in terms of rate of people infected per hundred thousand. We have a higher rate of infection in Santa Fe than we have here in Dallas, in Los Angeles, in Washington, D.C. In Albuquerque, it's a higher rate than in Detroit.

And what -- part of what's going -- and these are just our folks who are New Mexico counted at time of diagnosis. We have one hell of a lot of Texans, Colorado folks, Arizona folks let alone coast people coming into Santa Fe because word's gotten out that we're the San Francisco model of the rural place. And that's real problematic in terms of overloading good systems, one, and reducing what have been I think pretty good standards of care as that pool comes in.

I think one of the things that this National Commission and you, as Commissioners, really need to look at, is how to look at some of the models that have worked. I mean here again, we see that this year that our length of stay per hospitalization has done to six days in our state. We do have in-home hospice, you know,

hospice kind of care, plus in-home homemaker and nursing kind of services. And it's making a real difference.

And I would hope this National Commission would try to nationalize some of those effective models and what we're really towards down the road at I think is that this isn't just HIV. All people in terms of long-term care. We have been so lucky to learn and to see these new models that have emerged that they work and that they're cost effective. And we're really looking at national health care.

And I don't know how we can look at anything else and I don't know how you, as Commissioners, can do anything but hit that point over and over and over in spite of the fact that it may take awhile to get there.

Right now, this geographic stuff is really important for people with HIV and AIDS to look at in terms of their own wellbeing. It makes a whole lot of sense for folks who can possibly do it to take a look at what's out there, what their needs are, and where they can better get those needs met which is horrendous for putting together any kind of systems and planning for systems that

work at how many people you're going to have next year in your program, Jane.

It's counterproductive right down the line; and it's only going to get worse until we nationalize what we do, I think.

DR. LOVE: Let me ask that we move on to the issue of counseling and testing. Any comments on that?

MS. WILSON: I'll start.

DR. LOVE: Good.

MS. WILSON: I wanted to lay to rest a comment that was made earlier. And I just -- it's half true and half not true. And that is that I believe that counseling and testing has been successful.

In looking at in New Mexico the ten thousand people that we test each year --

DR. LOVE: A little louder, Jane.

MS. WILSON: In looking at the ten thousand people that we test each year, I think that we definitely do see a decrease in the numbers of partners over the years. We see decreases in the number of sexual partners for people who come back in for retesting because they've been asked to come back even though

they're negative.

We see increases in condom use from seldom and never to always and often. We see this both as a yearly trend hopefully meaning that some of our health education components are working. We also see it as a repeat tester trend that people who come back in for a second test are also showing increases or decreases in the amounts of risk that they're taking.

And, you know, I think that that needs to be said. I think that having said that, I think all of us realize that counseling and testing just simply needs to be strengthened and expanded. It really does need this extra component of post post-test counseling.

And I think that's what strengthens this. When I started looking at what are the weaknesses of the CTS program, it's that I'm only finding a hundred and fifty positives every year when I suspect that there's three thousand positives out there in New Mexico. That's a weakness.

And, obviously, this -- whatever we want to call it will probably get people in for testing that haven't gotten tested before. I think there

are issues in terms of counseling and testing for rural versus -- rural versus nonrural states. We hear an awful lot nationally that counseling and testing ought to occur in STD and drug treatment programs.

I concur with that wholeheartedly, but what we are finding in our STD and drug treatment programs is that the seroprevalence tends to be lower there than it is in some of our community-based testing sites and in some of our walk-in testing sites. And therefore, at least in New Mexico and maybe in other places, the people who come in voluntarily through the walk-in clinics really are the people who are most at risk.

I think the other issue that we have grappled with in New Mexico and that I fear in terms of the future is that we do have an anonymous testing program in New Mexico that I support wholeheartedly.

One of the reasons I decided on anonymous testing when we first got there was that there were seventy-five Mickey Mouses and Donald Ducks, two Jane Wilsons, and a Harry Hall that were positive. And I decided --

MR. SCHMIDT: I set up the Harry Halls.

MS. WILSON: Well, I was only there about six months when there were two Jane Wilsons that were positive and they were both male. I sort of said why are we keeping these records. I didn't want my insurance company notified either.

So, you know, we have done that. And I think the issue is, yeah, you can have all of these services, these medical services laid on top of an anonymous program. It's a voluntary approach.

People can get these post post-test counseling services voluntarily. Like other health services, we rarely provide medical care anonymously. And so, it would be confidential.

But one of the keys in terms of us is that people who get their CD4 levels in the public health department don't submit that for insurance. They sort of lie -- I think that's going to be a factor in terms of many of the PWA's. A lot of the stuff that is done through us will give people a lot of information about their medical status without having to submit it to insurance companies for repayment. So, I think

there are some issues in terms of that.

MR. DALTON: Jane, the real Jane. In a system that utilizes anonymous testing, how then do you get people in for post post-test counseling? I've been wanting to know since you first mentioned it.

MS. WILSON: We've been pretty lucky in New Mexico of having about an eighty-five percent return rate overall for post-test counseling, post-test counseling for results.

I think in terms of the post post-test counseling, that will be voluntary. We will talk to people about knowing what their immune status will mean to them and I think it does mean a great deal to them and then interest them in other kinds of things. I think good counseling can do it

MR. DALTON: When you say voluntary, do you mean you say to them one month from now call this number?

MS. WILSON: No, no. It's much quicker than that. I think when somebody is HIV-positive, we tell them we can offer a CD4 test to them, and, by the way, this is conceptual. It's going to be implemented this fall.

I think we're doing some of it now. We

tell them right at that point we can offer you CD4 testing which will show us and show you where you are in terms of the spectrum. We can draw it today. We'll make an appointment for someone to come back for that result and I think many PWA's will come back to that. That would be my guess if they're interested in that.

MR. DALTON: So, I didn't realize this hadn't been operationalized yet. The reason I'm asking this question is because of the sense that many people -- and even you yourself said it before that on the day of post-test counseling, that may not be their best day.

MS. WILSON: Yeah, it may not be. And what we may end up doing is asking them to come back on that. Although, we do have -- at this point, we've got a pretty active TB referral. And I think good counseling -- we do a lot of our counseling pretest. I think a lot of counseling is saying, look, if you're HIV-positive and then you need to know your TB result because if you actually are infected with tuberculosis, as your CD4 cells drop, you're very likely to get active disease, we could treat you now with one drug versus three drugs later. And I think people

respond to that and they do come back in.

DR. FRANCIS: But the issue you're talking about is there a problem with an anonymous person being positive going to a clinic confidentially for long-term follow-up?

MR. DALTON: No. My first question is: Do people hear any of that stuff? And they may hear it at that moment, but it seems to me that the day they receive their test results it may be the first day of the rest of their lives. But it's also one of their most confused and difficult days, and they're loaded with all that information. I'm not sure that that's the intervention point.

And the second point is once you -- I mean you can't call them if they're anonymous and get them into the system and follow-ups. And so, I guess I'm asking is there some mechanism for getting them back in?

DR. FRANCIS: It's very easy to walk down the hall; it's usually in the same place. If you took an anonymous person, you'd bring them down to sign their name up for their early intervention program.

MS. WILSON: Yeah, I --

DR. FRANCIS: It's generally not an issue at all. Once you're positive, then you've got a lot more concerns than getting people into the program.

MS. WILSON: I have no trouble getting people, for example, into the TB program for testing and that doesn't help them nearly as much in terms of maybe some of their concerns on that horrible day when they get their positive test as say being able to offer them CD4 testing.

But just letting them know there are some health concerns we've got to deal with now, people have been very willing for the most part to give us names, have us make appointments for private providers to get TB testing and that kind of thing. And that's all confidential.

DR. LEVINE: One way we get them back for testing, we offer them appointments at that first counseling. The local health department counselor offers them an appointment to work with a state contact notification staff. Okay.

There's a legal requirement that there be contact notification, that we offer to do that for them on their behalf so they don't have to do

it, in a very sensitive manner without revealing obviously the index positive.

And, of course, after the contact notification is completed, they'll just -- the whole list is destroyed and you can't trace it back. But, anyway, that gets them back again for another counseling session.

I did want a second to what Jane said. We feel our program is very successful. Our clients are referred by AIDS support groups to our counseling and testing sites, from the medical center, and from an awful lot of medical students and college students referred from the medical centers.

There's a tremendous benefit we feel to the counseling of the negative. These people who are worried about some risk behavior that they have undertaken; and that session with them is extremely useful, I think, and important from a public health point of view. So, we feel that the program, even with all its deficiencies and the lack of follow-up CD4 testing that we desperately like to do, it's still a very successful program.

DR. OSBORN: Yeah, I'm awfully glad to hear you say that because I think somebody much

earlier referred to the blood screening program as a model and I've always found it to be lacking sorely in that particular regard because the negative result is dealt with as if there were a final result. And as such, I think one loses almost the best opportunity to contain the epidemic.

And in listening to discussions of various kinds of testing programs, that strikes me as a consistent flaw. That's why Jane's emphasis on post post-test counseling is good.

But your answer about how you get people back disappoints me because you get them back at the point where they've already failed the system. And, as Don phrased earlier, there's a study that -- and I think I may be getting to be the oldest so I can talk like a senior citizen now.

There's an old study from when cardiovascular surgery was new about people undergoing elective coronary bypass surgery. But it was very elective, very scheduled, very -- as traumatically as such things can be and they agreed to be taped as they were counseled in advance by somebody who did a careful job of

trying to say what was going to happen to them.

And they were told in this study about an uneventful and successful elective surgery. And then about a month later they were asked what they had been told; all of the series of things of what they had been told, and their recall was about ten percent. And they insisted they had not been told the other things even though they could hear them being told on the tapes that existed. They still insisted that that had to be wrong.

So, since this is not being your best day is true no matter what the result is in a certain sense. And I think if we really want to take the people, instead of the virus, seriously we've got to start looking at some of the things we do know about how to do more effective counseling.

And the counseling of the person, in a negative person, the person who's tested negative, but who has come in to be tested because of some quietly perceived risk is probably the single most effective thing that could be done and very few of the programs that I'm aware of are focusing on how to achieve that.

And, of course, at least superficially

it's hard to get people to decide they should spend money for that. But I think that may be where one needs to help insisting that that is the most effective thing, not persuading somebody that they will secrete less virus in their semen if they're under care, you know. And that sort of thing troubles me greatly because we have missed what we're trying to do at that point.

And I think that what we want to be doing is -- I've been trying to think of something other than early intervention to talk about what we're talking about because I think without any question the phrase early intervention means AZT when your CD4 cell count goes below five hundred whether we like it or not, that is the way the Feds are using the term.

And what I think needs to be embodied is the concept that Don Schmidt voiced long ago that if you're already positive, the system has already failed and that that's a continuum and anything along that continuum that glorifies some arbitrary stage of it is a mistake in message, and, similarly, with counseling of HIV-positive as opposed to counseling people who perceive them as behavioral risks.

I think these all have to be considered that AIDS activism, people-oriented AIDS activism, some pro-active approach to the epidemic. I don't know what phrases there could be, but I don't suggest that early intervention be redefined because I think that's already operationally defined very clearly in the mind of the funders, if not the fundees.

DR. MASTERS: Yes. Jane mentioned that counseling testing sites in her state that it was your -- well, you thought they had been fairly successful in terms of containing the epidemic and that prevalence of people with HIV infection incidence was lower than what you had expected at other sites. I'm curious about syphilis in your state. Has there been a research of syphilis in your state?

MS. WILSON: We tend to have little outbreaks of syphilis. Now, I'm not in the HIV program so it's sort of what they told me six months ago; but we've had occasional outbreaks of syphilis, but not what I would call a resertive resurgence.

DR. MASTERS: The reason I ask you is that in Arkansas we have, based on our

calculations, have about -- have reported twelve thousand excess cases -- twelve hundred excess cases of syphilis since 1985. In this country, syphilis was declining for the last thirty years at two percent per year almost. And then in '85, there was an increase; and in '86, there was an increase.

And in Arkansas, we looked at sixteen thousand specimens that were submitted for both HIV and syphilis in the process of our State Health Department laboratory. And we found that the specimens who tested positive for syphililogy were five times more likely to also test positive for HIV. And that twenty percent to twenty-five percent of our people who were identified as being HIV-infected also have positive syphililogy.

I think one of the key things in this epidemic is that there is such a convincing link between syphilis and HIV. And we've done a terrible job in this country of controlling syphilis since 1986.

Based on the slope of decline that occurred over the last thirty-six years, we've had more than eighty thousand excess cases of syphilis in this country because we have not had the same

decline that we've had for years.

And I'm just wondering if we need perhaps to re-examine the strategies that we have been employing in terms of control as to these and not just focusing simply on HIV and putting people in a special group based on that.

MR. PANZER: I've heard people say it's two roles and you were asking us about the roles of HIV testing and counseling programs. One is the detection of infection in which a case if they were infected, the person would enter the system of care and the other was for the person who tested HIV-negative reinforcement of risk reduction and safer behavior.

And the system, the counseling and testing programs that have been put in place without some of the things that they're supposed to be entering into with their results.

And the problems that I have seen on a local level were -- first of all, one of the big problems is, and this is the return rate, you were asking about how many people come back to get the results. It seems that those at greatest risk for infection are having the worst rate of return for the results. And part of that is because of the

attitude or lack of skill on the part of the counselors. I think that very often it's the person who may be in a not very popular group who's treated poorly and is not going to return for their results. That's one of the problems that we've seen.

And as a corollary to that, it seems that people, especially in rural areas or small communities who are not counseling and testing people all day every day who see very few cases, don't maintain a skill level and that is a problem.

So, we see a tension between wanting to have counseling and testing in every site, in every little health department clinic, and having it available to everybody and being able to maintain the skill level who are not doing it very often. That has been a problem.

And I think, too, that their results have kind of reflected what Dr. Osborn's concern about supporting risk reduction behavior in those who are negative.

A lot of times in these clinics, the people are not willing to go into detail and may not have the staff resources to go into detail

with those who are negative and they are not being followed up either. And, so, there is the continuing tension between wanting to have it everywhere and having it at a high quality.

MS. WILSON: And what we find, too, is that people -- we have it everywhere. We have it in all the health offices --

MR. SCHMIDT: No, no, no.

MS. WILSON: Yeah, we do. We have it in all the health offices.

MR. SCHMIDT: Not in the high schools, not in the colleges.

MS. WILSON: No, but we have it in the health offices. And what we find is that a lot of people from small towns bypass their health office and go to the bigger ones that's sixty or eighty miles away for confidentiality testing.

MR. PANZER: We don't have any big ones so they're all small ones.

MR. GOLDMAN: When we visited Georgia, what was interesting in Georgia, it was interesting to know that even the health department itself sort of suggested to people that if they really wanted to get tested that they ought to go to some other county, but not the

county in which they reside if they wanted to be assured of confidentiality. And they set up a system designed in such a way so that you're tested in county X three counties away, and your county health office never found out about it.

DR. McFARLAND: I wanted to say just one more time that earlier when I talked about counseling and testing particularly in our own state not being the ideal situation and not working, I didn't mean that it didn't work at all. I mean that it needs to be augmented by services in a way to get the knowledge out to the people once they come in and we don't see them again.

And we do a lot of anonymous testing and I advocate anonymous testing, particularly in the New Orleans area of Louisiana. But to be able to find a way to get people back in -- and I've heard a lot of good things said today about getting that done, but we have spent an awful lot of money and I hope we'll continue to get money on counseling and testing.

But we've got to look at how to further that so that we can get -- and partner notification is part of that, too. We're

beginning to do partner notification and I'm sure other states have started it long before now. But to get the entire program looked at is what we need to do rather than spend all of our upfront money on counseling and testing.

MS. DIAZ: I just wanted to know if any of the states that are represented here today that have the standards for pre- and post-counseling?

DR. FRANCIS: I do.

DR. LEVINE: By law, that's an act.

MS. DIAZ: Okay. Just describe it for me.

DR. LEVINE: They cite the content of the counseling. They have to send you a copy of that.

DR. FRANCIS: Standards training have been approved counseling in California.

MR. PANZER: But there's a difference between the private and public sector. And in the public sector, there may be standards; and whether or not they lived up to, that's another matter.

But in the private sector, for example,

we had a man walk in to our center last week and the lab had done the ELISA test. The ELISA was positive. The results had been released to the patient. And the patient now goes, does this mean that I'm positive, you know, the lab said still this needs to be confirmed and all. Well, the doctor did not confirm before notifying and this is a private physician. So, these standards affect the public sector and not affect the private sector in the same way.

And I was kind of shocked that the lab which was a major lab, and I won't mention any names, a major lab in San Antonio didn't automatically have a protocol for doing confirmatory testing. And this guy was on tranquilizers. He was a mess, you know, and there was no standard in private sector.

MS. DIAZ: So, the standards are not across the board?

MR. PANZER: Right.

DR. LEVINE: In North Carolina, they're held to the same standard. It's law. It's the law of the state. There has to be confirmatory testing.

REV. ALLEN: I would like to

continue this; and for those who raise their hands who dispute, I would like for Nancy to take note of this. But I think we need about a five minute break because first off we need a break.

Second, is that I'd like it known to the public that we are going to have public comments at one thirty and here's an opportunity to sign a list in the back if you would like to speak, and we're going to have that from one thirty to two. So, let's take about a five minute break.

(Short recess.)

REV. ALLEN: We've got thirty minutes left before public comments and several issues we'd like to deal with. Would you go ahead and say what we're hoping to accomplish?

DR. LOVE: What we're going to do is focus on several issues one at a time and deal with them as an issue and then move from one to the other.

First, is the flexibility of the funding; second, is utilization of resources in an effective manner particularly as regards to intervention and to testing; and then third, we wanted to look at quality control or quality in testing.

REV. ALLEN: Okay.

DR. LOVE: The four of you that I promised.

MR. KELLER: There were some issues about anonymous testing or testing -- counseling and testing. I wanted to bring up the point that, you know, I think different states have certain different attitudes.

As far as confident -- you know, there's always been a long time argument between the difference between confidential testing and anonymous testing. And in our area, we found that -- we really found no difference and essentially have gone to a confidential testing system primarily for several reasons.

We didn't find that the fears that were all described that would happen if we had confidential testing really didn't become a reality. And we found and we also are of the belief that this is a behaviorally-transmitted disease and one needs to start taking and assuming the responsibilities for his behavior. And that comes with dealing, you know, dealing with the situations at hand.

The other thing that I think is the

biggest failure that's come about with the testing programs is I think they've done very good in counseling and their education process and the follow-up as far as sexual transmission, but they have failed miserably as far as the IV drug user situation has gone.

We have no access to at least even dealing with the behavioral problems of IV drug users. As far as sexual transmission, I think there's a lot of mechanisms in place; but essentially, we have no access to anything.

If somebody comes in and says I'm an IV drug user, essentially, all we do is test them, give them the results and they're out the door because there's no entrance into the system to deal with behavior itself. And I don't see anything coming down the road in the near future.

Speaking directly, there was some other comments about return rate as far as testing. We find that those individuals that come in on their own and volunteer to be tested, excellent return rate for results.

Those and many of the systems now push testing and so forth and essentially, talk the individuals into the test. Those are the

individuals that do not return, you know, specifically for the results.

And then there's those that debate what's the responsibility of your agency to inform them or not inform them. And with anonymous testing in that situation, you have to have some kind of identification mechanism where you can get back to them.

The deal about the syphilis decline is that we found in the last ten years, there is an increase. In fact, national is up three to three hundred fifty percent in syphilis. But what we have found in the last ten years is that it's not the same. We've seen a complete different population change as far as syphilis.

Ten, fifteen years ago, eighty percent of our syphilis was in the homosexual and bisexual transmission. Today, eighty percent of our syphilis is in the heterosexual, low socioeconomic and most is all related to the drug use and so forth. And that's a problem that we haven't begun to deal with yet. So, the population's changed.

DR. FRANCIS: I wanted to deal with June's comment about early intervention. It is clearly mine is very different in that I think

that our experience in other infectious diseases have shown to be fewer in full modalities in and around infected people instead of trying to deal with whole populations that we can be far more effective in primary intervention.

And I think we can justify early intervention solely on primary prevention. Secondary prevention comes from treating individuals I think is a gimme on that; but from my very narrow public health point, I think we can justify the entire program by getting infected people into long-term behavioral management both on voluntary testing programs on a person present, but also on voluntary programs in a more urging confidential setting where you actually bring people in and urge them to be tested; i.e., the drug clinics.

And then you center your early intervention programs around the drug clinics where there is something to offer them. And then you end up having in and around individuals who are HIV-infected, you are now identifying chains of transmission.

You come to the end of the chain of transmission with the infected person having at

risk behavior or the uninfected person. And that's where you zero in your prevention efforts in order to stop transmission completely. So, at least I --

DR. OSBORN: To respond briefly, my comment was intended to get us off the semantic argument not because -- I liked what you were describing.

DR. FRANCIS: I realize that.

DR. OSBORN: And I know that you have happened to have used the same phrase as did Dr. James Mason that early intervention was now a federally good thing to do. And he meant five hundred CD4 cell and EDT Pentamidine.

I don't think we should spend much time arguing about what early intervention means because that's what it's going to mean. It's going to mean what gets funding as early intervention.

But the concept that you put forward is a very much -- and the continuum of which that's one arbitrary cut that's been developed in this discussion is a good one. And my -- I wasn't intending to upset people who used to like that phrase.

I was simply saying let's not spend time with that phrase because operationally it's been defined by the assistant secretary for health for funding purposes.

And for us to try and commandeer it at this stage is probably not the best use of our time. So, I hope that I didn't get misunderstood in that regard.

DR. BOWEN: We redefined again at the last one when the bill is passed.

DR. OSBORN: Yes, but I think this conversation is so much different and interesting that I don't think getting into what early intervention is is a distractor that wastes some of the talent around the table. And that's the only reason I infused that.

DR. KONIGSBERG: Has the Federal Government, in fact, defined early intervention? I guess my impression is it has not. I hear your point that may be defacto.

DR. OSBORN: In June of 1989 as they stopped the study -- I forget which one it was. Nineteen whatever. I can't get those numbers straight. But when they stopped that, they announced that it was now possible -- Jim

Mason said it was now possible to do early intervention for people with five hundred T-cells and that this is what you did in early intervention. And you gave them for so long and that's early intervention.

Now, I've just been on the fringe of the Federal Government for long enough to think that that is going to remain a definition of early intervention in their mind for a long time to come. And if we're talking about something bigger, better, broader, we shouldn't be using that phrase the way they do because they won't understand it.

DR. FRANCIS: I split them into early intervention, prevent early intervention prevention of transmission.

DR. OSBORN: That's a strategy, but I think it's worth recognizing that if you use Federal buzz words, they're going to understand what they want to understand, not what you want to say.

MR. KESSLER: But we can't discount what the local public health departments or the county or state how they interpret early intervention. And sometimes not only on state

level but regionally, they set the tone and create the model that may be completely different than what Jim Mason thinks.

DR. OSBORN: My suggestion is that we have the opportunity to create a language and a tone that reflects the richness of this discussion. All I'm suggesting is to watch out for the pitfall of using language that already has a much narrower meaning in the mind of funding agencies than what you're talking about.

MR. KESSLER: I think that's what Fred was saying earlier and I guess I was saying, too, is that pitfall's not only around early intervention. It's also around the term public health is from.

DR. OSBORN: Right.

MR. KESSLER: Everybody is not a model. No one has a unified model that has consensus for the body.

DR. BOWEN: Let me just make a couple of comments about counseling and testing programs in general and then give you my -- our agency funds about a hundred million dollars worth of counseling and testing programs around the country. And obviously, I'm asked whether they

work or not.

So, I'd just like to respond to that question if I can. One, in terms of does it work or is it effective, you have to remember that we've had an evolution of what we've asked counseling and testing programs to do over the course of the last several years since 1985 with testing license.

It was initially a blood supply issue and then it became an initiated behavior change issue and then it became adding on notifying partners and then it became referral for medical care as treatment became available and then it's the context that we've been talking about early intervention here with the community-based response with psychosocial follow-up and mental health and referral to community organizations and behavioral reinforcement and case management and all of this richness.

So, asking whether it works, you have to frame it in these different contexts. So, that's one point to make. And they don't do the -- the system as we fund it does not do any of them perfectly and it does some better than others.

The second issue had to do with the

failure to return. We and others have looked at this a lot. And again, the best way to think about this was phrased by a couple of other people. One, is that if people come in voluntarily, they're much more likely coming in seeking testing and they're much more likely to return.

So, the post-test return rate is much higher for seropositive and seronegative persons where people have come in specifically seeking testing; but it is possible to reduce the failure to return problem considerably with careful counseling with attention to that issue in the counseling session if there's enough time to devote to it. One of the problems in STD clinics where the failure to return rate is high in many programs is that they don't have enough time to deal with this issue.

There have been STD clinic-based counseling and testing programs for people coming in for other reasons where the return rate is exceptionally high, over ninety percent. It can be achieved with careful attention to this in counseling and where there's enough time and where counselors really pay attention to this issue.

And men who have sex with men in general tend to come back better than other people who engage in other kinds of risk behavior. So, that's the second point.

Now, in terms of does it work to change people's behavior, let me just give a brief summary of what I believe is the best answer to that. We at CDC and others have reviewed all the studies that are purported to address this issue. Most of them are done in a cross-sectional fashion and really don't allow you to answer the question properly.

There are very few longitudinal studies. Most of the time, the persons that are studied -- there's a mixture between people who received counseling and testing during the studies and learn their sero status as a result of careful counseling and people who were or seropositive or seronegative at the time of the start of the studies, you don't know how long they've known their serostatus or what kind of counseling they got.

So, most studies are really not very good and are not designed to answer the questions. The few that are well done and

actually most of the ones that deal with men who have sex with men have concluded that there is a positive behavioral impact of counseling and testing. Most of them have concluded that seropositive men change their behavior more than seronegative men.

Now, in terms of the community demonstration projects of which Kevin O'Reilly is the project officer and kind of senior manager of this at CDC, they are about to publish a study of counseling and testing in the context of the five cities that have cohorts of men who have sex with men. And they focus their analysis on the men who are still engaging in high risk behavior at the time of recruitment into all these sites which are only a minority of the men. About twenty to twenty-five percent in all the sites.

And then they focused on people who knew their infection status at the start of the study and those that were informed of their infection status either seropositive or seronegative during the course of the study.

What they found was that people who were unaware and were found to be seropositive and delivered careful pre- and post-test counseling

most often multiple session counseling, even those men that were engaging in high risk relevant for transmission behavior -- and we analyzed this. Seropositive men, the relevant behavior is insertive anal intercourse without condom. And for seronegative men, the relevant transmissible behavior that leads to further transmission is receptive anal intercourse.

What they found was that seropositive men informed of their serostatus during the study changed their behavior very, very dramatically. Seronegative men who were informed of their serostatus, knew that they were seronegative at the start of the study also changed their behavior quite a lot.

And so, I think this kind of multisite study -- obviously, it's not representative of all men who have sex with men. There's the aging cohort phenomenon. There hasn't been in many studies a lot of recruitment of young men where a lot of us in public health are very concerned about young men, especially teenagers who are just coming out.

The last comment to make about the effectiveness of the counseling and testing issue

has to do with study with Tom Coates' group which was reported at the San Francisco meeting by Hoff, et al, in an oral presentation. And they talked about the issue of choice of partners by serostatus.

What the -- essentially the results were is that in a large number of cities, a larger and larger percentage of men who have sex with men know their serostatus. Over the course of time, a large and increasing number are engaging in long-term one-on-one relationships than had been true in the past.

Many of the investigators of cohort studies and other long-term studies of men who have sex with men indicate now that about half or more of men are in relatively long-term, stable relationships. So, this offers an opportunity for both choosing safe behavior and choosing partners by serostatus.

What they found was that seronegative men chose to be in relationships and actually were when they tested both partners in relationships with other seronegative men. Seropositive men generally preferred and usually were in relationships with other seropositive men, but not

quite as predominantly so.

So, what is happening is that there is a prevention strategy evolving that people are in a safe -- quote unquote, safe relationship because they're in relationships with persons of like serostatus.

Now, there was a lot of concern about seropositive men being isolated; and I think it was a very positive and important thing, too. We don't have want to have people isolated and separated from educational intervention by serostatus.

This is the kind of best response I can give you in terms of does counseling and testing work and some of the dimensions of it. I think it's not the only thing that Louise was talking about earlier. It can't stand alone. It has to be one of a series of community interventions. And it doesn't do everything for everybody; and it needs follow-up, but it does have some positive impact.

DR. MacLEAN: I'd just say under our HIV law that was passed last session, the health department discharged responsibilities with providing both anonymous and confidential testing

on a statewide basis albeit with major resources while Mickey Mouse and Donald Duck have been favored submitted to our laboratory -- this is in Texas -- Ronald Reagan and George Bush have been prominent submitters of specimens for analysis. My concern is that we just don't have the resources. And I've heard this around the table.

To take it one step further and provide the comprehensive care that these patients need despite the fact that we do have funds available for a very modest supplement of the Federal HIV Medication Program.

And by care, I mean if we wanted to get into our inner cities and deal with IV drug abuse problem and we do work with our center agency and substance abuse agency on joint projects for outreach for IV drug users and bring them in for counseling and testing.

It's not just the HIV-positives I'm worried about. We have a tremendous need in this state, and I suspect other states as well, for access to substance abuse treatment. It's just not readily available. You can't treat one without the other. You can bring them in and counsel them all you want to, but you can't put

that most difficult HIV-positive or even negative that you brought in into a substance abuse treatment program.

That can also add to the medical component that we were talking about for HIV intervention. You're almost wasting your time really. The most difficult thing we have to deal with in preventing the epidemic is what to do with our IV programs.

DR. LEVINE: What prerequisites do we have in North Carolina statutory and regulatory framework to undergurd a successful testing and counseling program?

So, I mention in statutory point of view presence of antidiscrimination statutes which are imperfect but do set out what the test results may not be used for in terms of discrimination, housing, employment, public access to public services and so on.

We also have required laboratory certification testing only be ordered by a physician. Content, as I said before, of the counseling are enacted in regulation. They are required -- including required the burden on the physician to provide the control measures to the

individuals as well as the obligation on the HIV-positive person. And so, very strong confidentiality provisions with appropriate intention.

And violations of any of those are a misdemeanor, a criminal offense in North Carolina with a potential for an unlimited fine and up to two years in prison. I'd be happy to make those available to anyone who would be interested.

DR. LOVE: Are there other comments about the testing?

DR. DYER: Just one brief one to get it on the record. I understand the Commission may look at this later. There are two wide a variation in the cost of the licensed CD4's ratios, P24's and so on in different parts of this country.

In Dallas, for example, a CD4 ratio two hundred fifty bucks. I understand some other parts of Dallas may even three hundred. I've heard stories of four hundred and fifty. And yet friends of mine say San Francisco is eighty bucks, sixty bucks.

DR. FRANCIS: Forty-seven dollars in North Carolina. They can send them there

anywhere.

MR. KELLER: Thirty-five in Nashville.

DR. DYER: I raise this point if we're talking about this maintenance program that's going to require a lot of people to have these recurrent medical tests. The costs of those are not uncontrollable and need to be assured that they are reasonable throughout the country and not only in terms of quality, but in the cost of those tests.

DR. FRANCIS: It's easier to control them just by publicizing the cost than it is to actually control them.

I have one more thing, short thing on testing. I think the standards for anonymous or confidential testing or pre- and post-counseling, I think you'd find a, relatively even at least, desire of where they should be.

Something that's revolving though is going to be, quote, the routine testing, the voluntary testing in prenatal clinics like how much pre-test counseling is going to be required there where these are by and large low prevalence and low risk group individuals. I think it's

going to have to be addressed soon.

DR. LOVE: Anything else on testing?

DR. GUERRA: I would just put a bid in to include testing for Hepatitis B as part of that effort which I think we have the same kind of moral obligation to consider. And I think that as more and more states are going to that as a routine screening in prenatal populations, I think it will hopefully encourage more of the HIV testing as well.

DR. LOVE: Charles, are you ready to pick up your point about funding?

DR. KONIGSBERG: Yeah. I've already said it, but I think that the Commission kind of needs to -- we've done a lot of discussion about the need to pour money into direct medical care. And this is one of the few discussions we had I think where money revolves around the whole prevention issue, you know, like the term early intervention.

I think we just need to think about what we want to say in a report coming up to the Federal Government and to the states for that matter about flexibility. I mean this is not a

new subject. A lot of this -- the restrictions that we get on all federal sources of funds from like MCA, those restrictions are actually growing as they come back to the accountability issue. And I understand that, but somehow it needs to be uncoupled from that so that it really doesn't -- we need to think about the kind of message we want to send.

And I get back to the point that if freed from the shackles of the restrictions that we've imposed on ourselves and what we get from the Feds our a little bit of AIDS money we have in Kansas, we could probably come closer to doing what we need to do, but closer isn't close enough either. I recognize it takes more money. That's all.

DR. LOVE: Other funding comments?

DR. FRANCIS: Just a quick one again on, I think, ultimately we should look for not only flexibility at the government level, but flexibility and choice for the individual in that I should have a menu of services required during the spectrum of continuing disease and that -- and then with the case management, you decide what are unmet in those and the individual then can go

choose and have a credit card or charge system, whatever, that they can choose what are the best ones that they want and then be reimbursed through a different service provision purchase order type thing than having to give big grants to organizations where the individual no longer has a choice where to go.

MR. SCHMIDT: Right on.

MS. WILSON: I would say also that this is one of those points where the availability of AZT and other drugs which will follow really does create a great deal of concern with the people who are dealing with prevention.

And as we are doing these kinds of programs, counseling and testing and the activities that come after that, we are going to be producing a large number of people who are going to be looking for availability of therapeutic drugs. And I think that is an issue in terms of our prevention efforts.

Otherwise, we are creating a crisis; and I think it's a well-deserved one. I'm not proposing that we stop counseling and testing because somehow someone's not providing us AZT. I think that's unethical.

So, I think we do have to look at that kind of therapeutic money and how it's going to be available so that we can do our prevention correctly.

DR. LOVE: Anybody else on funding?

MR. GOLDMAN: I just wanted to point out that at the Boston meeting of the Commission, the suggestion was made by some, and I think it was described as a scheme, that really what we ought to be doing is going out and doing as much testing as possible in the most agressive way possible so as to find the people who require the care which then in turn would drive the system.

And others suggested that that's not very ethical to spend all your money finding people who are going to drive the question.

DR. FRANCIS: The question is which is better.

MS. WILSON: I was going to say is less ethical to hide infection in the community because we don't have the resources.

DR. MASTERS: Just a word about the formula funding. Arkansas is a prevalent state

for HIV infection; but in formulas that I've seen that try to sort out what Arkansas would receive under various bills, it always seems that our state and states similar to us are hurt because there is a failure to take into consideration a higher cost of delivery of care in a rural type setting.

People who have HIV infection in rural communities have very, very few choices in most instances in terms of where they can receive care. If a physician who may be the only one in the county chooses not to see patients who have HIV infection, there is a burden placed on the patient to meet often long distances to a center where they can receive competent treatment. And that adds to the cost of providing care.

And the formulas that I've seen don't generally take that sort of situation into consideration. I think that consideration should be given to physician density in rural states because we get hurt.

In California, there are a lot of choices people can go to in terms of receiving care.

DR. FRANCIS: A lot of rural areas

in California. We got the same problems. It's a real problem.

MS. BYRNES: I hope you'll appreciate it and not take offense to the fact that I mention this. But Congress, who is a very active member of our Commission, feels very strong about that particular issue and has been very active legislatively in the new AIDS and HIV related legislation in Congress and to be particularly sensitive about that issue.

DR. MASTERS: The other thing I wanted to mention is that Arkansas receives about $70,000.00. And unfortunately, our state does not provide any kind of CD4 testing. So, essentially, we have money available for the use of HIV, but we don't have the tools to use it intelligently.

We did not identify those people who would most likely benefit because we don't have any money for testing.

MR. PANZER: It's the same in Texas.

DR. MASTERS: And if we had more flexible federal dollars, I think that that problem could be overcome and if we also had a more flexible state legislature.

MS. DIAZ: I think what we've heard this morning really clearly points out in my mind that a lot of the ways in which testing and counseling, early intervention, primary prevention and the blend of public health with the medical services that corresponds to an effective response have to be coupled with that voluntary effort and community-based effort that perhaps we haven't really focused on this morning.

And I'd just like to say that I know a very few places in this country that have actually put a dollar value to that community-based effort which is really driving a lot of the energy in local areas in response to HIV.

And until we do that, we will continue to have these kinds of discussions that say where is the federal pot of gold in the yonder, where is my state's contribution to that federal pot. And we will continue to discuss where is more foundation work.

But ultimately, that individual community has to organize around this, has to become vocal. I'm particularly concerned as a person in the minority community because a lot of that lesson of community-based effort is just

beginning. We're like five years behind the white or gay communities and being able to pull that support together. And without that, I don't think we can win this battle at the frontlines of where the need is presenting.

So, I really would like to make a plea for any of you that know where voluntary effort is being quantified in terms of dollars to let us know because I think it would be extremely important as we move into our further discussion into Seattle to look at models of care, the continuum of care that put together voluntary effort with public dollars.

DR. LOVE: Particularly appropriate that you're moving us from the funding issue into utilization of resources and not let the funding have the last word. Anybody want to make one last comment? Is there something that needs to be said that hasn't been said because we're out of time?

REV. ALLEN: I want to thank you all for being here. It's been very helpful to hear your comments and your particular situations.

At this time, we have an opportunity for the public to comment. We have some folks that

would like to make comments, and we ask them to come to the table.

MR. DALTON: Scott?

REV. ALLEN: Yeah.

MR. DALTON: Earlier you had asked people to sign up in the back. I was just thinking about in case Mickey Mouse or Ronald Reagan is here, there's people who are concerned about testifying under their own names. We should allow people to testify without identifying themselves.

And I yield to no one in my respect of the First Amendment, but the camera does worry me in that if there are people who would be uncomfortable speaking with a camera, maybe they could let him know and maybe something could be worked out. I don't want to miss anyone just because they are not coming out one way or another.

REV. ALLEN: All right. We're not inundated with folks here. We have two folks; and if they have any problems with being in front of the camera, we can certainly accommodate them. If there are others though that would like to, please see Jason in the back probably would be more

appropriate and discuss that; and we'll be sensitive to that and ask that the cameras be turned off at that time.

But why don't we go with the first person that would like to make a public comment and we would like to limit these to about three minutes for each and then some interaction afterwards. Dr. Murphy Solbrite from Austin.

DR. SOLBRITE: I've been listening to your comments this morning, and I've thought many of them were extremely appropriate. Let me give you a quick sketch of Austin and the AIDS issue to start with.

We have approximately six hundred AIDS cases at this point, half of whom are now deceased. We have another one thousand cases approximately which are now being followed by the physicians in the community. We estimate an HIV-positive rate in our community of approximately twelve thousand. That's an estimate.

Most of our HIV-positive population is still primarily male and gay. We do counseling and testing in the health department and in the community clinics.

We are at this point involved in two forms of early intervention. And we call early intervention very clearly what secondary prevention. In other words, once somebody's diagnosed as HIV positive.

We have a small clinic for women and infants. Basically, what we do is pick up the HIV infants after they have been diagnosed at the local hospital and we follow them and their mothers for eighteen months to two years until we know where things are going to go.

We have just opened with state funds for which we're very grateful an HIV-Positive Early Intervention Clinic for the general HIV-positive population. What we do is when we have done testing and counseling, we ask them are they interested in the HIV-positive clinic. If they are, they go over there.

It's only been operating for a couple of months, but the findings are quite dramatic. Our staff is already saying we don't know how we ever got by without this clinic. The impression of a patient with regard from a one-time counseling is so different from what you found out when you follow them and when you see them repeatedly and

you find out so much more about their problems, the complexity of the problems and the situation that they deal with.

We are also the center for what's called The AmFar Central Texas University which we work very closely with. We have a very close involvement with the private physician network.

Let me just sort of tell you generally what we think we need. For the private sector in order for them to stay involved, they need assistance with laboratory money for labs, money for pharmacy and assistance with case management. One cannot expect them to carry that alone.

For the physicians, one also needs continuing education. They will carry the AIDS patients if one can provide them with continuing education and AmFar contacts.

In the community, we need more early intervention, more clear counseling, more early medication and look at how early medication may improve our quality of life. Case management is essential. That is the end.

REV. ALLEN: Thank you. John.

MR. THOMAS: I'm John Thomas and I'm the Executive Director of Dallas Gay Alliance

AIDS Resource Center and Nelson-Tebedo Community Clinic for AIDS Research.

In Dallas, as many other areas, it is still predominantly affecting the gay community. In Dallas, ninety-three percent of the cases are still gay and men.

As far as public health and early intervention, anonymous and confidential HIV counseling and testing was requested to be done in our community center for years until we finally had to do it ourselves.

In February of '89, an arsonist's fire destroyed our center; but we still started our HIV counseling and testing. In June, we expanded it to a second deck. About a hundred people a month are coming to our center for anonymous counseling and testing. They have to pay $20.00 cash because we have no funding.

T-cell testing and monitoring. We offer it at cost which is about one and a half to five times cheaper than private physicians in Dallas. So, when people get tested and find out their positivity, they then are encouraged to get early intervention and find out their status.

Access to clinical trials. As Don

pointed out, what is early intervention when you're dealing with opportunistic infection? Early intervention may be that you are already diagnosed with AIDS, but you want to not get some of the other OI's.

We have clinical trials, AZT and acyclovir. And yet they're available for people who have private physicians. Indigent people in Dallas County will not be referred to our clinic for clinical trials. Therefore, that is withholding a hope and a health and a right from indigent people with AIDS and it's withholding taxpayers the best use of their funds.

What I would hope from this group as far as public health officials and the whole issue of early intervention is that we need more public visible, verbal leadership. It cannot just be the AIDS activists and the gay activists that are going down to county commissioners, going to the state legislatures. We need public health activists.

We want you to start being more concerned about saving lives than saving your careers.

MR. DALTON: Before you go, when

you say that indigent patients are not referred to you for your clinical trials, why?

MR. THOMAS: We wrote a letter asking for an explanation so that we could tell the PWA's who asked to be in the clinical trials and have never received a response. That was two months ago.

MR. SCHMIDT: Not being referred by who? By this hospital primarily?

MR. THOMAS: Correct.

MR. SCHMIDT: Why am I not surprised? Coming to Dallas, I was reminded of Howie Dare and Phil Gerber and more recently Phil Morrow who it seems to me -- none of them are still alive, but it seems to me that the ongoing battles with getting response from Parkland, I hear more about than hospitals in any other of the major cities. I'm not surprised. I'm saddened. I really hope they respond to your letter.

MR. THOMAS: Well, that was sent two months ago by our medical director of the clinic. But I also want to address that in the early years of the epidemic, we referred people to come to Parkland because they were the ones who had the best care and the best knowledge.

What has happened is that the public health officials are not holding the county commissioners, the city council, the state legislatures responsible for funding so that they can expand the way that this epidemic has expanded. And then that's what happens with the indigent people. They then can't get into clinical trials, they can't get the care that they could in the early days of this epidemic.

REV. ALLEN: Are there any others that want to make comments?

MS. DIAZ: Do you know of any clinical trials in this area?

MR. THOMAS: There is a rifabutin study within the hospital and there are private physicians that are working with -- within community base, no. We are the community-based group that AmFar funded such as the one in Austin. And we actually are looking to expand to include folks from Louisiana and Oklahoma and New Mexico because they also are looking for access to clinical trials.

I mean for a state to be the fourth highest in the incidence of AIDS and not to have a federally-funded AIDS clinical trial group is

really criminal. I mean how can we totally ignore Texas, and the surrounding states, but Texas when we have that many cases.

And I brought it up to our Congressman and he said, but I'm not into pork barreling. I said I'm not talking about pork barrelling. We have if you want to call them guinea pigs, people who want to participate and not have to travel at government expense to NIH's to participate here in Texas. And I think that we cannot miss the point that early intervention on OI's, on opportunistic infections is an area that NIH hasn't been really agressive in either.

MR. PANZER: I just want to make a comment on people in public health and the public health sectors as activists. I found the same problem in South Texas in that many of the providers in the public health sector feel that their hands are tied by their agencies, that they cannot be advocates on behalf of the patients that they're serving.

And I'm wondering is there some state -- in particular the people who are working with Texas Department of Health seem to have some inhibition or something in being an advocate on

behalf of the patients.

They recognize the needs. They say we are underfunded. We are understaffed. We don't have the proper facilities. And yet, they don't make noise in Austin. And then we try to make noise on their behalf and they think we're giving them substandard care.

So, it seems like a catch-22 situation. I don't know if Dr. MacLean can address that because it's a real problem in identifying the need and sending the appropriate resources to meet that need.

DR. MacLEAN: Certainly, at the state level, there's no word out not to be an advocate in your community. So, the more resources, the more management AIDS of the problem.

At the state level, our hands are tied a little bit in that we're not allowed to lobby. Even those government officials are not allowed to lobby, but that doesn't mean that the community themselves can't organize and be a very effective voice as to what their local community needs.

The folks on the hill when they're in session -- and they think about AIDS through all

the other hundred of things that are unfunded in this state or underfunded in this state right now -- need to know what it means in their community. So, when they go home, they need to hear from the folks out there, not the folks in Austin.

You know, the commissioner can go down there as he did last session and plead to get $36,000,000.00 for the biennium for AIDS which he did and he got lots of yawns. But out there in your community, your center's representative wants to hear as to what it means for them.

And our thirty-six million that we asked for got whittled down to eighteen point four, only fifteen of which was new money. And I think one of the reasons was we just didn't have enough community support out there telling these folks that vote what it means to vote for this as opposed to voting for that in a year when they didn't have enough money for anything.

As you know, through our last special session, we just barely squeaked by. We would have had to shut down had we not gotten that emergency transfusion. So, the force that they listen to or what interests them is what's in it for my community and they need to hear from you.

REV. ALLEN: You have a comment?

MR. PANZER: I was just going to say that you can bet there are local officials here from the community-based organizations. There is still a need even on the local level, not even at the legislative level for -- as John Thomas is saying for people in public health to become advocates in the community. And that's -- that has been lacking in our community, too. I'm just trying to echo what he has said. It's not a single viewpoint. That's definitely true in smaller towns.

REV. ALLEN: It was definitely lacking in the last session. The public health's voice was not there.

DR. MacLEAN: Well, I think the public health voice has to be at the local level. I said that all along. In the broad problems that we're facing, I see the public health leadership at the local level has been critical to facilitate.

As we said in the earliest session today bringing the various diverse groups together to address the problem when no one group has enough resources to handle the problem, I think our local

public health -- in many respects, I agree with you. I think they could do a more visible and more effective job.

REV. ALLEN: Larry, then Eunice. Then we have another person that would like a comment from the public.

MR. KESSLER: I wanted to address your question because I think it's important. What we have found and I think all across the country is that public health officials generally had their hands tied when it comes to lobbying the legislature. One of the budget parameters have been set by their secretary or by the governor or whoever.

But that doesn't stop them. I think from exercising some flexibility and what I would call the partnership that ought to exist between the community-based organizations and the AIDS activists of all sorts, the health providers and so on and public health because they can feed you the statistics, the numbers.

And the case is bad enough not to exaggerate. I think one of the things that I think has happened in some cases is the local CEO or whoever exaggerates the case and then they have

egg on their face.

But if you tell the truth and you tell that based on the real numbers that your local department ought to be working with you around and feeding you, then when the rep calls back to confirm, everybody's in sync because the public health department will not fail to give information to the local rep or the senator because they need them to support the budget request that's already in.

But a thinking health department can get that budget expanded by using the activists groups and the community-based organizations as well as the physicians, clergies and the media. I mean we need a three- or four-way partnership here because the story has to be told and retold so that when they're voting on the budget, they can say to the local department of public health, you didn't ask for enough. Forty-seven million isn't enough. You should have asked for two hundred million.

You know, we have seen as we have traveled across the country, and I can speak from my own experience in the northeast, it works very well when DPH hits the wall in terms of what they ask for. They give us the information and we go

in for the next strike, you know, through the budget process.

And, of course, a lot of the CEO's haven't been attuned and don't know the budget process and that's a priority for them to get sensitized to and up to speed. Then they can be an advocate for expanded public health response and not the enemy.

REV. ALLEN: Eunice.

MS. DIAZ: Yes. I think, Larry, it has to go much beyond that. True that ammunition in terms of data and statistics and how people can use these for advocacy is important, but public health leadership around this country as long as I was in public health was a very effective weapon and an army of individuals that are trained in community organizations and community education and organization skills.

And those are health educators, professionally trained to bring about change in a community looking at ways in which needs assessment build on the strategizing skills and mobilization to get things done.

And I'm wondering what has happened to the use of the traditional health educators,

public health educator roles that had the skills to be able to mobilize and work with community's constituents and get those kinds of changes and mobilized.

It's true, Charlie, that one point that individual may and -- and tour of the community may need to step aside but still provide some very important staff assistance and background that goes beyond just being able to give the group some incentive can you fly with it, but to literally mobilize the individuals to represent their interests.

And that's the kinds of mobilization that's going to be needed to work through local problems and difficulties and challenges posed.

REV. ALLEN: Charlie.

DR. KONIGSBERG: Yeah. I think Larry Kessler was really -- I think we can say that again, Larry, or put it in writing at some point of that type of partnership. I found this particular interesting in listening to the discussion between the local health officer and the representative from the state public health department having recently left the local level and moved to the state.

And I've gotten a number of doses of reality orientation. And one of them is that it was awfully easy to -- it was much easier to be a, quote, activist at the local level particularly when one was looking at the state than it is once one is at the state and which is why Larry's point and Eunice's both are real important.

What I found in our state is a very strong advocacy for children -- mothers and children. And it was no accident that our legislature in a very difficult year, perhaps not as difficult as Texas, but tough, put a million dollars of new money into the nail care which for our state is an astounding industry. Yet, we had to fight to keep what little state money we had in AIDS.

And that's -- and I guess to pick up on Eunice's point and trying to put it with Larry's which maybe I'm reaching a little bit to do that is that we've got to do some work as the state agencies to make those community-based organizations responsive also.

Responsiveness works both ways. And I mean it's a two-edged sword. And we're not always going to agree and there will be times for

squabbling and this and that, but I think if -- I think that the ends are the same.

I think it's terribly important. But our hands are often tied. It's one thing to say well, sacrifice your career to be an activist. We could all sacrifice -- if the people who are affected all sacrificed their careers, you won't have any affected people in there. So, we've come to a blend. It isn't just being the one standing.

MR. KESSLER: It's more of a question; and that is, what's happened to leadership? Part of it is we have political appointments who are more concerned about protecting the politician than who appointed them than the public health.

However, I have also seen, you know, local reps and senators respond to a breakdown by zip code because they thought that all people with AIDS were in another part of the county, not in the zip code that they happen to represent.

So, something that simple can sometimes open up their eyes and say oh, my God, it is in my district and it is affecting my constituents, not just across the track.

REV. ALLEN: Due to the sensitivity of time, we also have another person. So, let's go on with this next person. Tom Emmanuel. And you have three minutes.

MR. EMMANUEL: Hello, my name is Tom Emmanuel. I'm a registered nurse. I'm the AIDS Nurse Clinician here at Parkland in the outpatient clinic.

I've been with the program here since its inception about four years ago and have seen many changes from -- both negative and positive changes. And one thing I wanted to mention about the drug trials of the community-based clinic is there are a lot of physicians in Dallas who see patients with HIV infection who are not sending clients to those drug studies.

And part of that may be their own personal choice; but again, physicians have to be concerned with the efficacy and what the possible outcome of those studies are.

Also, there are drug studies that are available here at Parkland; and I'm sure if anyone would like to talk with Dr. Nightingale about what is available here, I'm sure he would be glad to spend the time with you.

Rapidly, some things that I think that we need here in Dallas, we need more money for case management, both for hospital-based programs as well as community-based organizations. We also need more money for home-care hospice and out-of-hospital services.

We do receive money from -- we do contract with the Visiting Nurse Association through state and federal monies for home care of indigent patients. And they do supply a lot of services, but I think that we do need more money for home-care services.

And lastly, I'd like to bring up that we do need more money for research for children and women. We're starting a women's clinic here so that the mother and child can be treated at the same time here at the hospital so there's better follow-up for both of them.

And I think there needs to be more research available for women and children. Thank you.

REV. ALLEN: And we have one more person. Carol Howard.

MS. HOWARD: Good afternoon, my name is Carol Howard; and I'm also a Registered

Nurse that works in the AIDS Clinic at Parkland. And I'd like to say first that, you know, I'm not going to comment or complement Parkland's AIDS Clinic because I work there, but because the work they do is so good. I really feel the doctors and all the staff, the entire staff provide the best services that's possible to my clients. And I think our clients really appreciate and know that.

But today, I'm here as a volunteer representative for a minority community-based organization that was started in April. And the name of that organization is the Multi-Cultural Health Coalition. And I heard someone earlier mention Phil Morrow's name. Well, I knew Phil Morrow. Phil Morrow was one of the people that helped get that organization started.

And the reason the organization was started was to provide support and encouragement for minority persons living with HIV and AIDS and also to provide education and prevention information to the high risk groups, adolescents, IV drug users and other minorities.

Today, I just want you all to know that we've applied for a grant from the Center for

Disease Control. They had an announcement that they were going to fund thirty new organizations, cooperative community-based organizations. And they were looking all over the United States to provide funding for those thirty.

And in -- with that in mind, the Urban League, the Multi-Cultural Health Coalition and AIDS InterFaith Network wrote a grant together. And we submitted that grant in May of this year. We haven't heard anything back from it, but the purpose of the grant is to fund the Multi-Cultural Health Coalition.

Presently, the work that we've done is we've started two support groups: One for men and one for women. And the support groups are growing at a phenomenal rate. Everybody that works with the group, they're volunteers. But what we found is that once the support groups were in place, that the people started coming. So, it was obvious that the need was there.

I've met a lot of people since I've been working with HIV and AIDS, and I've seen a lot of people die; but I do know that with encouragement and support that people want to live. And that's all they're looking for. And it's hard to give

support and encouragement without some type of funding.

We need an office open that we can be there for the people. We have a voice mailbox at this time, and we have a P.O. Box. And we're working on a pamphlet to pass out, but the word is getting out about our organization.

But we do need a full-time staff. And our grant did request funding for three full-time positions and two part-time positions and office staff. That's it.

MR. ALLEN: Thank you very much. I want to thank all of you for being here and for helping us and sensitizing us to the issues. It's helped the Commission to get out of Washington to come here and to get your expertise, your wisdom. And we're very deeply grateful, and we will put it to good use. Thank you very much.

(End of Proceedings.)

STATE OF TEXAS

COUNTY OF DALLAS

THIS IS TO CERTIFY THAT I, LAURIE S. KOKORUDA, a Certified Shorthand Reporter in and for Dallas County, Texas, reported in shorthand and transcribed to the best of my ability the proceedings had at the time and place set forth in the caption hereof, and that the above and foregoing 219 pages contain a full, true and correct transcript of the said proceedings.

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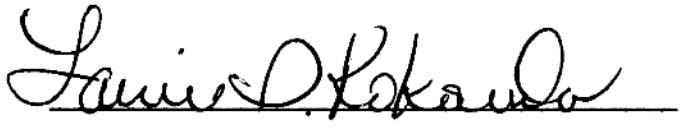

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