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Joseph O'Neill, M.D., M.P.H.- Chief Medical Director, Division of HIV Services, Health Resources and Services Administration

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Ms. Marie St. Cyr- Executive Director, Women and AIDS Resource Network, Brooklyn

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Mr. Romeo Sanchez- Human Rights Specialist, New York City Commission on Human Rights

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John W. Ward, M.D.- Special Assistant for Science (HIV), Centers for Disease Control, Atlanta, GA

Mr. Bob White- Deputy Director, BEBASHI, Philadelphia, PA

Mr. Wayne S. Wright- Exeuctive Director, Multicultural AIDS Coalition, Boston, MA

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MORNING SESSION

CHAIRMAN ALLEN: My Name is Scott Allen. Let's go ahead and get started.

Good morning. I would like to welcome you all to this working group meeting of the National Commission on Acquired Immunodeficiency Syndrome. We are here order to provide an opportunity to look at the a variety of issues associated with HIV epidemic in this country, to look at the certain issues in depth and report to the full Commission on this working group.

I am Chair of the working group and at this time I would like to introduce the other members of the group: Larry Kessler here is the co-founder of AIDS Action Committee here in Boston, and most of you probably know him if you're from the Boston area.

Eunice Diaz is the Associate Professor of Family Medicine at the University of Southern California. She has worked extensively with the Hispanic issues across the country.

Harlon Dalton is a professor at Yale Law School and the editor of "AIDS And The Law".

Don Gold professor man is a lawyer from

New Jersey and is the Past President of the National Hemophilia Foundation.

And Doctor Ron St. John is from the National AIDS Program Offices, also here with us today.

I think this would be a good time to go around the table and to let you all get to know each other. Since I did not tell you my background, I am from Dallas, Texas. I am an ordained minister that is a founder of the AIDS Interfaith Network in Dallas, and also a part of the AIDS Arms Network, the case management program in Dallas. I have been on city, county and state task forces dealing with the AIDS epidemic. So that is my background as well.

Why don't we go around and introduce ourselves.

DR. CAULEY: My name is Kate Cauley. I am with the AIDS Policy Center in Washington, D.C., where we attempt to monitor and analyze all legislation in the states related to HIV infection.

MR. McEVOY: My name is Jim McEvoy. I am with the National Association of

People With AIDS out of Washington. I stand in support of the AIDS Action Committee in Boston. Also I am co-founder and Executive Director of the Boston Living Center which is a self-help resource center which provides drop-in facilities and activities for people with the HIV infection.

DR. ST. JOHN: I am Ronald St. John. I am with the National AIDS Program Office and Office of the Secretary of Health and Human Services.

I am Peter Smith. I am Associate Professor of Pediatrics at Brown University. I have been involved with hemophilia and co-founded the hemophilia program in Rhode Island and have been very active with the National Hemophilia Foundation.

DR. O'NEILL: I am Joe O'Neill. I am currently the Chief Medical Officer for the Division of HIV Services in one of the bureaus at HRSA. I have been in this job about five months. Prior to this I was working at the County Hospital in Seattle in the HIV AIDS clinic as a primary care physician and also worked as an

HIV testing counselor for the Department of Public Health.

DR. MAZZUCHI: I'm John Mazzuchi. I am with the Department of Defense with the Office of the Assistant Secretary For Health Affairs; most specifically, I am principle director of the Office of Professional Affairs of Quality Assurance. Ours is the office that has had primary responsibility for developing policy with regard to HIV AIDS infection for the military.

MR. DALTON: I am Harlon Dalton. I am a law professor at Yale University.

CHAIRMAN ALLEN: Anything else you would like to share?

MS. GELFAND: I am Jackie Gelfand, ATS Project Director of Gay and Lesbian Community Services in Los Angeles.

MR. JOHNSON: I'm Wayne Johnson. I am an instructor in statistics in epidemiology at University of South Carolina School of Public Health.

DR. CLEARY: I am Paul Cleary. I'm with the Department of Health Care Policy at the

Harvard Medical School. I've analyzed a number of testing programs in the United States. I'm currently director of a program to provide information and support to persons who test positive for HIV infection. I'm participating in a large study of the cause and outcomes of different patterns of care for persons with AIDS in Boston.

MR. ENGSTROM: I'm Eric Engstrom. I'm Executive Director of the National AIDS Network. We are best known for annual skills conference that assists volunteer-based organizations in terms of management and service. Prior to accepting that position in December I was co-executive director of the Minnesota AIDS Project, which was a statewide AIDS prevention project.

MR. WHITE: I'm Bob White. I am presently the site director of our new county test center in Philadelphia. Prior to that I was coordinator of case management services at our community health center.

CHAIRMAN ALLEN: Excuse me, our court reporter is trying to take down everything we say, and she is having difficulty with the speed at which we are speaking; also, I would assume with the background noise. So let's have a little compassion for her and try to slow down a little.

MR. LEVI: My name is Jeff Levi. I started in AIDS work at the beginning when I was a Washington representative for the National Task Force. I became its executive director and was that until August of 199. Since then I have been doing AIDS policy consulting for a number of organizations, including AIDS Health Crisis, AIDS Action Council and a project with the Institute of Medicine.

DR. HINMAN: I am Director for the Centers For Prevention Services at the Centers For Disease Control. Our center handles the AIDS prevention as well as STD control.

MS. AFFOUMADO: I am Executive Director of the Community Health Project in New York. This is my seventh year in the epidemic. My main areas of expertise are in community-based medical management for the diagnosis and treatment as well as comprehensive and coordinate models for continuum of illness for all people with the infection.

MR. GOLDMAN: I am Don Goldman. In addition to my private practice of law, I do some work in areas of medical ethics. In addition, I am also Vice President of the National Health Council and have been involved with issues involving responses by voluntary health agencies in terms of issues of chronic disease and care.

MR. WRIGHT: I am the Executive Director of the Multicultural AIDS Coalition here in Boston. We focus our energies on issues of communities of color and, more specifically, educational strategies that work within the communities. I sit on a number of boards here locally, including The Hospice at Mission Hill, the Governor's Task Force on AIDS, and the Boston AIDS Consortium.

DR. NOVICK: I am Professor of Biology at Yale and Chairman of the Mayor's Task Force on AIDS in New Haven. In that capacity, I function principally as a person who attempts to develop services in health care for minority persons and IV drug users. I am also the

Chairman of the Ethics Committee of the American Association of Physicians For Human Rights, which is primarily concerned with promoting health care of gay men and lesbians.

MS. STRAWN: I am also from New Haven. I am a nurse and am currently working as the Agency Director for the Community Health Education Project, which is a NIDA-funded AIDS education demonstration project for substance abusers and their partners. I am also on the clinical faculty of Yale School of Nursing and set up the first alternative testing site, anonymous testing site in Connecticut, which was in 1986, and ran that project for Yale. I'm very involved with an interested complimenting therapy, particularly for minorities and IV drug users.

DR. WARD: I'm John Ward. I'm Special Assistant for HIV Science at the Centers For Disease Control in Atlanta. I've been working on various epidimiological studies of HIV infection since 1984 at the CDC. My primary research interest has been in transfusion-associated infection, and as part of that research interest, I have done a number of studies on the evaluation of HIV antibody and antigen tests in screening persons for HIV infection.

DR. MAKADON: I'm Assistant Professor of Medicine at Harvard Medical School. I work at Beth Israel Hospital in the Outpatient Department where we have chosen not to have a separate AIDS program but have integrated the people with AIDS and HIV infection into a general and primary care practice. I am also the Executive Director of the Boston AIDS Consortium, a group which was founded two years ago and now involves about 400 individuals and 100 participating agencies looking at planning for health care and human services with AIDS and HIV infection in the Greater Boston area.

MS. DIAZ: I think Scott has said enough about us as members of the Commission, but in addition I am Vice Chair of the Los Angeles County AIDS Commission and recently appointed to serve as an advisor to HRSA in their newly-created AIDS Advisory Council. Thank you.

MR. KESSLER: I'm Larry Kessler,

Executive Director of the AIDS Action Committee here in Boston and a member of the Massachusetts Task Force on AIDS as well as the City of Boston Task Force and the AIDS Consortium here in Boston. I welcome all of you to Boston on behalf of the rest of us Bostonians.

MS. ST. CYR: My name is Marie St. Cyr. I am the Executive Director of Women and AIDS Resource Network in Brooklyn, New York. I was previously the Director of the Haitian Coalition on AIDS. My work involves education, counseling and support to women in the communities as well as to different sections of the Haitian community in New York City. I am also a member of the Board of the National AIDS Network as well as the international liaison in Haiti.

MS. BYRNES: I'm Maureen Byrnes. I'm the Executive Director of the National Commission on AIDS.

CHAIRMAN ALLEN: At this time we will introduce Marc Roberts. Marc is going to be our facilitator this afternoon. Marc works as a facilitator and moonlights at Harvard as a professor of some sort. So we are grateful to have you here, Marc.

In the past year we have seen some heartening development, with improved prospects for a longer life and better quality. Although we are far from ready to present AIDS as a chronic management disease, we are progressing on a hopeful course.

I have to say that the terrain has changed somewhat as we look at testing and early intervention; that now that we are seeing some medications coming forth and some new dynamics developing, it's appropriate for us to revisit the issue of testing and intervention. So we have brought you here because you are on the front lines. You have had experience in this, and we are grateful for you being here and taking the time to come and help us as Commissioners.

We are here to learn from you and we are here to interact and join together in the task of trying to deal with this disease.

I would like to say from my perspective that this disease, as I look at the statistics, they are more than just statistics. These are peoples' lives, people that have died that are very precious, that it's very sad. So I am concerned that we stay on course with looking at the realities before us and not get off into the theoretical journey but to say what really works, what do we need to do to stop this epidemic because there are also peoples' lives that are in the balance right now, that are waiting to see what we can do to stop this epidemic, that are perhaps infected right now saying my life is in your hands, to a certain degree, what are you going to do with it.

We also have folks out there that aren't infected, and the urgency there to keep them from becoming infected; then balancing that with the societal needs of saying how to respond as a society to this epidemic and how can we stop it.

I would like us to open up with the testimony at this time, we have testimony from four sources, and we will begin today with the panel of presenters to help us start with a common understanding of certain basics associated with the HIV testing.

Doctor Paul Cleary will provide a broad

overview of the topic. Doctor Kate Cauley from the Intergovernmental Health Policy Project at George Washington University will discuss the various state and legislative trends. Ms. Marie St. Cyr from the Women And AIDS Resource Network will discuss the challenge of testing in different populations. Doctor John Ward for the Centers For Disease Control will review the types and standards of the various HIV tests. There will be a brief time for some questions and answers after each presentation.

There has also been a request for the presenters to go up to the podium since there is some type of audio need at this point.

DR. CLEARY: Good morning. I am delighted to have this opportunity to raise some issues. I also would like to act on Reverend Allen's comments that this should be based on the needs of people. I would like to emphasize that my comments will not be academic concepts or concerns but rather are driven by my experience over the past several years of more than 800 people that we have worked with, provided support to. So this is a very deep issue for me.

Available screening techniques for antibodies to HIV are very accurate and, if used appropriately, have the potential of helping to reduce the spread of HIV infection and may provide information that could result in better medical treatment for some individuals. Frequently, the rationale for screening usually has not been explicated clearly, and programs have been implemented in a way that limits their potential effectiveness. Discussions and decisions about HIV testing seem to have been driven more by political and ideological considerations than by careful analysis of the goals of such programs, the potential impact that they will have on individuals and the public health, and the ways to maximize their effectiveness.

I will review a number of considerations that should be part of any such analysis. It is important to emphasize first, however, that screening programs often can serve multiple purposes, and it is important to consider the efficacy and effectiveness in achieving each of these goals.

Four broad goals that frequently arise in this repect are: Public Health - to provide information to infected individuals that would help them maximize their own health outcomes and reduce the chance of transmission of HIV infection to other; Clinical Treatment - to provide information that would help individuals and clinicians make clinical decisions; Others' Right to Know - to provide information to providers that would help them reduce the risk of infection to themselves; and Epidemiology - to provide information about the course of the HIV epidemic. I will discuss the first three of these today.

HIV antibody tests will be most effective if used in situations that minimize the relative number of test errors, if they are administered to as many high risk individuals as possible, if they are used in situations that result in the maximum amount of new information and in which efficacious action is possible, and if the way in which the tests are used increase or maintain the public's confidence in the medical and public health systems.

In addition, the purposes, implementation, and consequences of a testing program must meet the ethical standards of our society. In general, a careful analysis of the potential benefits and harms from the test should support the argument that the proposed program is the most effective and efficient way to achieve the stated goals and is ethically acceptable.

I will now discuss some of those issues. Let's first speak about test accuracy. The utility of a screening or diagnostic test is obviously a function of the accuracy of the test. When screening for HIV infection, there are a number of reasons the test may be inaccurate. The most commonly used HIV screening tests are antibody tests, and a person may not have antibodies to HIV at the time of testing and any test will give an inaccurate result in at least a small proportion of cases. I will not dwell on that topic today because I think it has received a disproportionate amount of emphasis in the public debate about testing.

It is important to note that although a series of HIV screening tests can be extremely accurate, the relative number of errors will depend on the prvalence of HIV infection in the population being tested, and it is important to conduct a careful and realistic evaluation of the likely number of false positive and false negative results that will occur in a given population.

Next I will talk about participation. Assuming that one had an appropriately targeted and efficacious testing and counseling program, it would be desirable to maximize participation by high risk individuals. Although this principle probably is self-evident, the features that would maximize participation are not obvious. What is well established is that there is often a great deal of misunderstanding about HIV testing and that many people are very fearful of both the results of the testing and of breaches of confidentiality.

For example, a recent study of seropositive blood donors indicated that a quarter did not realize that their blood was going to be tested, in spite of substantial efforts to implement informed consent procedures.

Even when individuals are knowledgeable about HIV testing procedures, concerns about confidentiality may limit participation by high risk individuals. A study in Oregon found that the availability of anonymity increased overall demand for testing by 50 percent. The overall figure would have been substantially higher except that the increase in demand was only 17 percent for intravenous drug users.

Another concern many individuals have concerns the notification of sexual contacts. A study in Japan found that about 30 percent of students and workers and 45 percent of homosexual males would refuse to be tested if test results were to be given to the government.

The next topic is new information and effective action. It is very important to evaluate the marginal usefulness of any screening test in terms of the new information provided and/or behavior change. That is, given what the patient knows and what the provider knows about the patient, does the test yield important new information and are there effective responses to that information? Tests have the greatest positive impact if the results lead to clear actions to prevent further transmission of the virus or specific clinical interventions in the interests of the patient that would not be taken in the absence of test information.

If a patient is an intravenous drug user and evidences an opportunistic infection characteristic of AIDS, then the physician would know that the patient is almost certainly HIV-infected, without the benefit of an antibody test. Even if the patient had significant risk factors for infection yet showed no evidence of infection, the physician probably should behave as if the patient were infected in terms of providing behavioral counseling to the patient and taking precautions to prevent the spread of current or future infection. Conversely, a person in a very low prevalence area of the country who reports no risk factors is almost certainly not infected.

In the first instance, the test would yield little new information; and in the second, the test would not result in behavior that was substantially different from what would be done in the absence of test information. Similarly, it would be extremely unlikely that an HIV test would provide new information to the low risk individual described.

In situations in which the test does provide new information, either positive or negative, it is important to consider whether that information can be used in an efficacious way. The data are mixed as to whether many existing testing and counseling programs result in important behavior changes.

For example, McCusker and colleagues found that awareness of positive HIV antibody test results was associated with slight reductions in certain behaviors, but not others. A major limitation of our knowledge in this area is that almost all published reports of the impact of HIV testing and counseling programs have involved self-identified high-risk homosexual men.

A related issue is that the risk behaviors for HIV infection or subsequent transmission are very complex behaviors and inherently difficult to change. Methods for counseling seropositive individuals currently are being evaluated and it is not yet known how to intervene most effectively with seropositive individuals. It is clear that this is a complicated task requiring familiarity with many of the complex clinical and behavioral aspects of HIV infection. Since many physicians are not well trained in these areas, this is an important limitation to keep in mind when planning a testing program.

I will now address the cost benefit ratio. The above considerations are important to consider in combination when designing an HIV testing program. In addition, there are several general principles that should be considered. Testing usually is recommended only in situations in which it is the least costly or restrictive means of accomplishing a particular clinical or public health goal. Implicit in such considerations is a rigorous cost-benefit calculation: The potential benefits and specific consequences of testing; the potential costs and detriments; the attributable prevention of using the test versus opting not to use it; whether comparable outcomes can be achieved at lower personal, social, and/or financial costs.

The basic ethical principles of respect for individuals, beneficence, justice, suggests that the purpose of the screening must be ethically acceptable; the means must be appropriate for accomplishing the purpose; individuals have the right to be informed of the results; confientiality must be protected; sensitive and supportive counseling must be available before and after testing.

Certain types of programs would entail significant social costs. For example, drawing blood and testing against a patient's express wishes is contrary to the core values of the therapeutic relationship; trust and voluntariness. To upset those values in a case where there is not prophylactic public health purpose in preventing disease may not be justified.

A feature that is rarely mentioned when clinical testing programs are evaluated is the symbolic impact that such a program will have. A positive impact on the public trust might be that a group who previously felt neglected thought that the issue of HIV infection was being carefully addressed and that societal resources were being used to try and stem the epidemic in that population. If, on the other hand, a testing program were viewed as an inefficient, inadequate, or a punitive program, this would be an important negative impact of the program. Such a negative outcome is undesirable from a societal or ethical point of view.

In addition, there may be very practical reasons for avoiding programs that negatively affect the public trust. Public health efforst are inherently collaborative efforts that require public acceptance and participation to be effective. From this perspective, a program that precluded such participation might seriously compromise a wide range of related public health efforts.

An example of a bad policy with respect to these principles is U.S. policy regarding travel and immigration. The policy restricting travel and immigration violates international law and global health guidelines. From both a global and a national perspective, testing and exclusion of international travelers is a specious public health policy, for it does not reduce the reservoir of infection in the world or alter high risk behaviors. This is especially ironic, considering that U.S. citizens have and will continue to spread more infection to other countries than vice versa.

This policy does not meet the standards specified earlier as evaluation of false positive and false negatives; encourage participation; provide new information and precipitate effective action; enhance public confidence; cost-benefit ratio; basic ethical principles.

Perhaps one of my most fundamental and important conclusions is that in any testing program, patients should give explicit consent to be tested and should have the opportunity of refusing testing, even in situations such as a needle stick injury, where an intuitive analysis might suggest that testing should be conducted irrespective of the patient's wishes.

Some physicians argue that there is no need to obtain informed consent for an HIV test because no physical harm results from a serologic test. Information that must be disclosed to the patient has usually been confined to physical risks, not social harms. Consent is critical because of the particular contemporary personal and social significance of HIV infection, however. Serious psychological and social consequences are just as relevant for the patient as are physical effects of the diagnostic or therapeutic interventionl.

HIV test results are, without question, relevant to important health care decisions and have serious psychological and social consequences. As with many medical tests that predict grave or fatal diseases, some patients prefer to know the information, while others do not. Some patients who are informed that they are HIV positive, particularly if they did not even know they were being tested, would bear an intolerable psychological burden.

There is a real risk of severe emotional consequences, even suicide, following an HIV positive test result.

There are also serious social consequences of a positive HIV test that need to be weighed carefully by reasonable patients against the potential personal benefits of knowing their HIV status. The justification for fully informed consent to HIV testing, then, is that it respect a patient's autonomy and privacy in law; it complies with well-accepted clinical standards of care by providing a critical opportunity for counseling and education; and it maintains the ethical integrity of the medical profession and dignity and worth of the patient.

Screening tests have the best performance when conducted within a population or subgroup with high prevalence of infection. Unfortunately, it usually is difficult, if not impossible, to define groups at high risk of HIV infection without being presumptuous or discriminatory. Many high risk behaviors are stigmatized or illegal and any effort to identify persons who engage in them would likely lead to discriminatory practices or procedures that would alienate those at greatest risk of infection from the medical care system.

These issues are highlighted if one considers proposals for routine testing of all hospitalized patients. Concerns about the risks of nosocomial infection are legitimate and must be addressed. Every effort should be made to improve the universal precautions already in effect. The available evidence suggests that in spite of the increasing risks to health care workers, many still fail to consistently exercise routine cautions. Research into techniques for lowering the incidence of needle sticks and surgical injuries must be expedited. Programs designed to educate health professionals about procedures and techniques for avoiding exposure to blood need to be implemented to further reduce the existing risks of transmission.

In-hospital programs also should assess the important questions of risk perception and provide for effective interventions. Furthermore, health professionals should have a greater opportunity to assess the significance of working under conditions in which uncertainties will, of necessity, persist. Only by clearly and openly addressing these concerns will it be possible to develop a set of rational hospital responses to the epidemic.

If we are to slow the transmission of HIV in the United States, it is important that we identify, educate, and counsel as many infected and seronegative high risk individuals as possible. Since hospitals have the technical capacity for HIV testing, hospitalization can provide an optimum opportunity for screening individuals. However, the most important aspect of any screening program must be to maximize the probability that the test results lead to positive behavior changes. These conditions will be achieved only if patients are assured of anonymity, or at least confidentiality with no possibility of subsequent repercussions and if the screening program is followed by a well-developed and careful counseling program.

My specific recommendations to the Commission are that more work should be done to coordinate and monitor standards for HIV screening test protocols and enforce those standards nationally. One problem that has caused a great deal of confusion is lack of uniform standards for certain tests, for example. More rigourous procedures should be established for monitoring the performance of laboratories performing tests. Monitoring programs such as those conducted by the American College of Pathologists could be extremely useful in this regard.

Programs should be developed to train health professionals concerning the advisability of testing for different types of persons, the interpretation of test results, and the meaning of HIV infection. These programs should train physicians, nurses, and other health professionals in such topics as the epidemiology of HIV infection, and the natural history of HIV infection.

Programs should be developed to train health professionals concerning how to provide support to and encourage behavior change among seropositive individuals.

In order to maximize the impact of testing programs, they should in almost all cases be voluntary and anonymous. If it is not possible to insure anonymity, rigorous procedures should be established to ensure confidentiality.

The importance of developing training programs for medical and paramedical professionals cannot be overemphasized. We all share a common goal of reducing the spread of HIV infection. Since the virus can only be spread, for all practical purposes, by a limited number of behaviors, it is critical that we focus extra effort on developing strategies for modifying those behaviors among all individuals and especially among HIV infected individuals.

CHAIRMAN ALLEN: Doctor Ward, we will save questions until later. Does anyone have a question for Paul at this point?

MR. DALTON: Early on in your remarks, you mentioned a study involving people who appeared at blood donor sites. You said that 25 percent, I think, didn't realize they had been tested in spite of informed consent. Are you saying that all of the 100 percent of the people were given informed consent prior to being tested?

DR. CLEARY: I'm referring to our work at the New York Blood Center, and the population, just seropositive individuals. All persons tested are given information about testing and in fact sign informed consent procedures.

When we counsel HIV-infected confirmed positives, we ask them, did you realize that your blood would be tested. The number has increased over the past three years, but it is still about 25 percent who say no, they didn't realize.

MR. DALTON: Tested at blood donor sites?

DR. CLEARY: At blood donation.

MR. DALTON: Is it your understanding that these people were in fact given an informed consent but didn't remember it, or is this a common --

DR. CLEARY: It's my understanding that everyone was given an informed consent. They were told about the test and were given pamphlets. But in many cases it's material people don't attend to or don't understand.

The point is this is very complicated information. These kinds of information and follow-up is often done in a very perfunctory way and is not adequate to maximize HIV testing.

MS. DIAZ: Just one question. I wanted you to repeat your statement about the testing in hospitals, and I'm concerned that the hospital population would just yield the same results as general population because we don't have any data to say that they would be in higher prevalence status.

DR. CLEARY: I'm sorry, I do not understand.

MS. DIAZ: The statement that you made regarding the possibility of testing in hospitals. Could you just repeat that? That wasn't clear. Why would that not yield the same amount of false positives as testing in general populations?

DR. CLEARY: I think testing in hospitals would be as accurate, if not more accurate, depending upon the prevalence in the area of testing in the population.

MS. DIAZ: You weren't suggesting that that should be done, correct?

DR. CLEARY: No. I would suggest that screening in hospitals should follow the principles that I laid out. That high risk individuals should have testing. I think the primary concern is to distinguish between routine testing, mandatory testing and confidential or anonymous testing in the context of a clinical relationship. I would favor the latter, and I would emphasize that if any testing is done, the only way to potentiate its impact is very carefully constructed information and counseling and support programs. I do not support routine or mandatory testing.

MS. DIAZ: But you would be in favor of identifying high risk patients that come to a hospital?

DR. CLEARY: I think in the context of a clinical doctor/patient, nurse/patient relationship, individuals should be informed about HIV infection. They should be made aware of opportunities for testing for HIV infection, and should be told of the potential risk and benefits of that testing.

CHAIRMAN ALLEN: One more question.

DR. SMITH: What are your thoughts about testing for children? We tend in this state to be rather liberal. We realize that early identification is probably very important.

DR. CLEARY: I think that's a very good consideration. I would probably follow the same ethical principles that we follow in terms of other procedures and tests, and either with the mother or the guardian engage in a discussion about the benefits of doing that, the availability of therapeutic intervention.

CHAIRMAN ALLEN: Thank you very much. Doctor Ward from the CDC.

DR. WARD: Good morning, everyone. It is a pleasure to be here. I've been asked to make a few remarks regarding the scientific aspects of testing both in terms of what types of tests are currently available, how they are performed and how well they perform.

The first test that was licensed for use in the United States was licensed on March 2 of 1985. They were HIV antibody tests. Since that time, they have been shown to be highly sensitive and highly specific tests. As a result of that, they have been recommended for an increasing number of public health uses as well as clinical uses. And, also, because they perform so well, they remain the major way of identifying

HIV-infected persons, in spite of the development of other types of assays that I will briefly describe.

Currently, there are eleven tests licensed by the Food and Drug Administration to identify HIV-infected persons. All eleven of those are HIV antibody tests. Nine of those are based on one type, which is known as the Enzyme Immuno Assay, or EIA. I want to briefly describe what an EIA test is. All of these nine assays use disrupted whole virus, where they throw the virus in the culture, break up the virus and place it on beads, and then you add the patient's serum to those beads or wells. And if the antibody specific for the HIV virus is present, it will latch onto these bits and pieces of the virus there and remain there.

Then you add a second antibody, which is very specific for human antibody, and that latches onto the human antibody. So you really develop a sandwich, and that's why you have a sandwich assay. Attached to that animal antibody, which identifies the human antibody, is a compound that when you add a solution to it will cause that solution to change color. It's the intensity of this color reaction that determines whether the test is found to be positive or negative, based upon a cutoff date that's determined by the manufacturer. The intensity of the color reaction is measured with a special system. It's an automated system. It gives you a numerical value that is important to keep in mind because you can use that value to determine the intensity of the test and help you decide if the test is truly positive or falsely positive.

Another advantage of these tests is that they are very short to perform. It will only take you about four to six hours to perform a test. Now, the test value that's above this cutoff value is called a reactive test. All reactive tests should be repeated. If it's repeatedly reactive, it's called a positive test, and all positive tests should be confirmed by the use of a second additional test, either a Western blot assay or an immunofluorescent assay or ISA.

Now, the sensitivity of these ISAs has been shown to be 98 to 99.5 percent accurate the

Food and Drug Administration testing panels. Persons who may be at increased risk of being found negative, even though they are infected, or persons who have been recently infected with the virus and have not yet developed a detectable antibody that can be picked up on the test, or in very late stages of AIDS that the immune systems have been immunized that the antibodies have dropped below the level. The specificity of the test also has been shown to be very high.

In the study that I did that was published in the Journal of the American Medical Association, we came up with an estimate of 99.85 percent specificity. That's the ability of this test to remain negative when testing uninfected persons. In summary, when you look at the test itself, specificity and sensitivity are very high.

The other thing you want to know about a test is what is the predictive value of a test. The test itself does not determine that. The population that you're testing determines the value of that. In other words, if you get a positive result, what are the chances of that individual being positive or being infected. And that is determined by part of the risk for that individual to be positive. That is an important reminder, that you always want to know the clinical background of a person whenever possible when testing someone. That is not always possible in certain screening programs, but clearly in a clinical setting you always want the background.

Now, the specificity of a test may be influenced by several factors of the person so they may get false positive reactions in women who have had children, for instance, people who have received multiple blood transfusions, and some other medical conditions. But for the most part, these tests function very well.

The Western blot assay, as I mentioned, is the test that's performed most commonly to confirm the result of the EIA test. The Western blot is also an antibody test. It also uses disrupted or broken up virus, which is spread on a piece of paper. That's why it's called a blot. Electric current is passed through that which allows the various proteins of the virus to migrate out on the basis of their molecular weight.

You place the patient's serum on this paper. The antibody, if present, will bind to the specific proteins, and you get specific bands along this paper corresponding to where the antibodies latch onto the various spiral proteins. This banding pattern is very specific for HIV-1 and for HIV-2, for that matter. In that way, the Public Health Service has issued guidelines as to what bands need to be present in order to call a Western blot positive.

The Western blot is used as the second test because it's very, very specific because of these banding patterns that are so specific. The problem with the Western blot is that you get a fairly large number of indeterminate results where you can't tell if someone is truly positive or truly negative. In that situation, it's recommended that you get a second specimen a few months later to see if the banding pattern has become more specific.

And one ELISA test should never be used to confirm the results of another ELISA test.

In regards to the proficiency of laboratory testing, the CDC initiated a program back in 1986 called the Model Performance Evaluation Program where we regularly send out proficiency programs to, in 1989, we sent out 1400 proficiency panels to laboratories to see how well they do in testing for HIV antibody. We then, these specimens are blinded, some are positive, some are negative, by our laboratory, and then when we come back, we collate the information and send back out the test results to these participating laboratories so that they can see how well they are doing in relation to other laboratories.

We also collect additional information from these laboratories, including the types of test kits they are using, the types of confirmatory tests that are being used, other HIV antibody tests that may be available in that laboratory setting, and we regularly publish that data, and the 1990 edition just came out last month. I will be happy to provide that to the Committee on request.

One other test that's currently available to test HIV persons that may be at risk for HIV infection is the HIV antigen test. This detects the virus itself in the blood rather than the antibody. But it's very similar in design to these other EIAs, and that is it's a sandwich assay except it's starting with virus. And if the antigen is present in the serum, it latches on and you identify it again through a color reaction.

The antigen test can only detect free antigen. And for most of the course of HIV infection, HIV antigen, or bits of the virus, are also complex antibody, and the antibody covers up the antigen. It doesn't allow the antibody to identify the antigen.

The only course in detectable quantities is very early in infection, before antibody has been produced by the body, or very late in the course of infection, and that's why it's frequently been mentioned as a prognostic marker for the development of AIDS, as the development of detectable HIV antigen. It was also believed that perhaps the HIV antigen test can help us identify better, and was an issue promoted to be a second test that could be used by blood banks to identify persons who were infected but did not have detectable antigens.

We recently completed a study with the FDA and major blood banking organizations to show that the HIV antigen test has little, if any, benefit in screening donated blood. And as a result, when licensed by the FDA, it was recommended that it not be used to screen donated blood and plasma in the United States. So right now, the HIV antigen test has fairly limited capability.

Several other tests that are available is chain reaction, which is a research test that can identify HIV specific DNA in specimens, and HIV culture, where you place lymphocytes from infected individuals into a culture media and assay for replicating the virus. The PCR is a very sensitive test. As a result of that, false positives are a problem. The HIV culture test is only accurate in about 85 to 95 percent of seropositive individuals and has very limited clinical or screening utility.

So, in summary, the HIV antibody test,

particularly the enzyme immuno assays, continue to be the mode that we use to identify HIV-infected individuals. These are antibody tests and continue to show really superior performance in comparison to some culture methods or antigen methods. Thank you very much.

CHAIRMAN ALLEN: Any questions?

MR. LEVI: You mentioned the annual efficiency study of laboratories. I think that is a critical issue if we are going to be considering wider use of antibody testing. It is one thing for it to be a highly accurate test at the CDC or NIH, but it's important to know the real world experience.

This is a two-part question. The first part is if you could share with us most recent data that you released?

DR. WARD: The problems that we have identified have not come from the proficiency of the participating laboratories, for the most part. They tend to function very, very well and having a high concordance with our proficiency panel of testing.

The problem we have identified has been in the way that these results are communicated to the person ordering the test; that it may not be in a way that's understandable or that's clear and, in fact, is in some cases flat incorrect in the way it's presented in terms of giving the clinician sufficient information to know what that test result really meant. It wasn't clear, as an example, whether a Western blot was done to confirm the ELISA, which is definitely a necessary second test and needs to be performed.

MR. LEVI: Are you saying that the physician wasn't told whether or not it was done, or are you saying that labs weren't necessarily doing it?

DR. WARD: The lab did the second confirmatory test but did not communicate that to the physician. And that's important information for a clinician to know, obviously, because in the situations, if you have a laboratory that's not doing that test and you assume that they are, that needs to be up front and explicitly stated so they know exactly what tests were performed. So I think that is a very real problem.

The other problem may be, although it's

something a little out of the realm of the laboratory, but I think the laboratory has some obligation to instruct the Commission as to what those tests mean, what they can and cannot tell. It's not clear to us how well clinicians are interpreting that data. If you can't interpret data, you shouldn't order it, but you can't guarantee that.

But as far as our proficiency testing, there was some concern about how well this information was being presented to the clinicians.

MR. LEVI: The comment which you made, no physician should be ordering a test that he or she doesn't know how to interpret or doesn't understand what its implications are, and that is a fairly frightening prospect, particularly if we are talking about much, much wider application in conventional care settings of the test.

The follow-up question is there are also these quick tests, there's at least one that I know of, that have been licensed, and that does not involve sending the specimen to a laboratory but can be done in a physician's office, at least the initial test before a confirmatory test.

Has the CDC done any proficiency testing in that regard in terms of -- I don't know whether the people who do lab work in a doctor's office are more or less well-trained than those in the laboratories. Have you done any studies in that regard?

DR. WARD: As you mentioned, there is only one licensed test that is a short, rapidly read test, and that's the Cambridge Bioscience Assay. There appears to be real problems with that assay in terms of it's very important that the technician performing the test have expertise in reading the test. It's a subjective test.

As I mentioned, most of these antibody tests will give you a numerical value, which is a subjective test. These tests have to be read with the naked eye, so it's very subjective as to whether the color reaction is of particular sensitivity to be called positive. You need a very bright light source, for instance, and a technician who has done a number of these tests.

Our proficiency panel, there are very, very few of our 1400 participating laboratories that use the test. So very few of these labs use this test, so we don't have a real idea among our proficiency panels how well this test is doing. But there have been a number of published studies demonstrating problems with reading this test and getting the correct answer. And the FDA is actually working with the manufacturer to identify what the problems are with the interpretation of the assay.

CHAIRMAN ALLEN: Excuse me, Jeff, if you could save these questions for the round table?

MR. GOLDMAN: First of all, I have one very quick question. I want to know whether or not the IFA has the same specificity and sensitivity as the ELISA.

DR. WARD: I've never seen any studies with immunofluorescent assays as far as specificity. The problems with the IFA, they are no available standardized free agents. There is a licensed Western blot assay that people can use as a second test. People who have good familiarity of IFA and in processing their own reagents, those laboratories do show very high levels of sensitivity and specificity. But since there are no standardized reagents, the Public Health Service favors the Western blot since you do have them that are approved by the FDA.

MR. GOLDMAN: I would like to ask you another question. Would you suggest, we're talking about dealing with policy, I don't think we can be focused on what the current technology is today right now at this very moment. We have to talk about what kind of tests are likely to be available over the next reasonably foreseeable future, what their sensitivity, specificity, availability, what kind of settings those tests might be able to be done from a technical perspective.

Do you have any thoughts on where the world of testing will be from a technical perspective, say, three to five years from now?

DR. WARD: I think there will be a greater number of these rapidly read assays that will be coming down the pike. There are a number that are in development by a number of different companies. They are based on common protein technology. They are using synthetic peptides, which are just proteins which mimic the configuration of proteins in the HIV virus, or you put the genum into bacteria and the bacteria will begin to produce the viral proteins that you want to incorporate into these tests. That makes it highly likely there will be increasingly more cleaner tests.

So I think what you'll see as far as antibody testing is concerned will be, there's several tests that you can read within ten or twenty minutes now that will probably be much more commonly available in the very near future.

MR. GOLDMAN: Will they have the same degree of specificity and sensitivity as the ELISA test?

DR. WARD: It certainly appears that way. Whether you will need a second additional test for those, that will remain to be seen. I think you will still probably want to do that and maybe delay the final result as it has currently, as the Western blot takes usually a day to perform. But you will get more rapid read tests in the future.

CHAIRMAN ALLEN: Excuse me. We are getting crunched for time here. Harlon had a question. If you could write down the question, and bring it up to the round table. We have two more presenters and a time crunch here.

MR. DALTON: This has to do with the possibilities for standardization. As I recall, you said that the Public Health Service guidelines -- Is it possible to have some standardization?

DR. WARD: The reason that the cutoff is set by the individual manufacturer in the ELISA test is that each test will give you a various cutoff and you use various positive and negative controls to determine the cutoff. So the cutoff is determined in consultation with the FDA before the test is licensed and how that cutoff is derived. But you derive it as part of the instructions.

And the Western blot, as I said, we have tried to standardize the interpretation of that test because it is a subjective test. The IFA will, I think, in the near future will continue to be a problem because it's not a test that is being done in very many places. There is no way I am aware of to standardize reagents, that I am aware of. But the laboratories that are familiar with it, it is a very good test.

CHAIRMAN ALLEN: Thank you. And John is going to be with us for both days.

Doctor Cauley? This is on state legislative trends.

DR. CAULEY: I appreciate the opportunity to speak with you. I might just begin my comments by suggesting you all have copies of my speech if I speak too quickly or certain points need to be clarified.

As was mentioned, I represent the AIDS Policy Center in Washington D.C. We have been monitoring and analyzing legislation in the states related to HIV/AIDS since 1983, although the Center has officially been in existence since 1987. I took the liberty of also distributing the most recent copy of our newsletter that is a general overview of all 1989 legislation. I hope you will find that interesting and useful.

Essentially, I would like to identify what has been happening with the states in terms of legislation around testing, both from a historical perspective. What I think you'll find is that most legislation in the states is directly or indirectly related to testing in some way. I suspect that is self-explanatory. Any measures designed to protect public health rely on knowledge of a person's HIV status. The protection of individual liberties frequently drives procedures to insure confidentiality of reporting and disclosing HIV test reults.

Overall, legislation in the states related to HIV/AIDS has been relatively consistent. The trend has been towards emphasizing the need for voluntary testing based on informed consent with pre- and post-test counseling, bolstered by strong protections of confidentiality of the HIV test information. And policies have generally been designed to reduce impediments to individuals who seek testing and to encourage people to make the selection to be tested.

Additionally, within some special populations, particularly prisoners or prostitutes, as examples, some legislatures have authorized testing without consent of the individuals. And even fewer states have actually mandated that testing must take place. The legislation has been consistent in prohibiting use of HIV tests to restrict access to care or services.

One of the first pieces of HIV legislation related to testing was drafted in California in 1985, and in fact it required the designated counties offer HIV testing free of charge on a confidential basis. At this point, most, many states are reflecting this desire to encourage voluntary testing. They have offered various alternative test sites, anonymous testing, confidential testing. At this point there are 17 states who have legislated that testing be available both on a confidential level and on an anonymous level so that people had a choice.

Proponents of anonymous testing, as we heard in previous speakers, argued that people are much more likely to be tested when the opportunity for anonymity is present. A study in Georgia, for example, demonstrated that following the introduction of anonymous testing option there was a 50 percent increase in the demand for testing, and twice as many seropositive persons were identified in the first three and a half months following the introduction of anonymous testing.. I think that's important to remember.

And another factor that the states have been including in legislation has been the necessity for pre- and post-test counseling. In fact, 24 states now mandate that there will be pre- and post-test counseling with testing, as our previous speaker has pointed out, that's not always a guarantee that people receive the information but the legislation has required that. An example would be in a 1989 law for Maryland which provides for pre-test counseling with the test subject, including education about HIV infection, transmission and prevention methods, information about the physician's duty to warn, and assistance in accessing health care for individuals who test positive for HIV infection.

In New York, pre-test counseling also includes information regarding confidentiality protections that extend to HIV related information, and discrimination that may occur if unauthorized disclosures are made, as well as legal remedies that are available to prevent unauthorized disclosure.

In Texas, post-test counseling is specified in legislation to include a face-to-face meeting, which addresses the meaning of the test results, the possible need for additional testing, methods of transmission, the availability of appropriate health care services, mental health care services, et cetera, in the patient's geographic location, and a discussion of the benefits and availability of partner programs.

As the epidemic grows, more and more states move into moderate to high prevalence status in terms of number of reported cases, thereby intensifying the the need for voluntary confidential and anonymous test sites and appropriate pre- and post-test counseling. We see in the 1990 legislation that that is exactly what's happening. More states are introducing into this current legislative session either improved or changed laws to encourage voluntary testing, or new laws to encourage voluntary testing.

Before I address the specific differences in the state legislation about voluntary versus authorized or mandatory testing, I would like to make some definitions that are germane to my remarks only. In referring to state legislation, when you talk about screening, you're talking about epidemiological kinds of programs where this is anonymous process and people are simply being tested to attract the disease.

In certain legislation when we talk about routinely offered testing or routine testing, we are identifying legislation that would mandate a particular institution to routinely offer to anyone who comes into the institution the opportunity for testing, but not to require it.

And then when we're talking about authorized testing in state legislation, that means that an institution or individual is empowered to require that a person be tested first requesting an informed consent, and if that is not granted, then having to follow the standards of due process procedures of court orders.

And finally a mandatory testing, which is in very few state legislations, again, assuming that there will be an attempt initially to an informed consent but that every person is tested who comes into a particular institution. I will define that a little more clearly later.

States have in fact taken steps to insure that people are able to make informed choices about being tested for HIV free from coercion and undue influence and with full understanding of the test's purpose and implication. Led by Massachusetts in 1986 and California, Hawaii, Illinois, Maine, Oregon and Wisconsin, in 1987, 31 states now require written informed consent before an HIV test can be performed.

Some states have begun to offer routine testing for certain populations. Rhode Island, for example, offers routinely HIV tests to its hospital patients and individuals seeking family planning or prenatal care services or individuals applying for marriage licenses. Testing is also offered to patients routinely in Rhode Island of drug treatment centers and clinics for the treatment of STDs.

There are four general areas of exception in the state legislation to required written informed consent which include: Testing performed on blood, internal organs, tissue or sperm, which may be used for infusion or transplantation purposes; testing performed in a medical emergency when the patient is unable or unwilling to provide consent, and the test is needed to proceed with appropriate medical treatment; testing performed following a significant exposure to an infected individual; and, testing performed as a part of anonymous research or anonymous test site.

Eleven states now have legislation that requires that all blood, internal organs, sperm and tissue donated for transplantation be tested, and some states have provisions that within that context donors are required to provide written informed consent.

Additionally, nine states routinely require written informed consent of any blood or tissue or organs that are donated. I think it's also important to note that -- well, never mind.

In a medical emergency, there are in fact seven states that allow HIV testing without consent, and there are a number of states which allow HIV testing without consent when it is necessary for appropriate medical treatment and the patient is unable to give consent, or a representative of the patient.

If a health care worker or other worker is significantly exposed to blood or body fluids of the patient, there is an exception to the required informed consent rule in the legislation of the states in nine states. However, the legislation of these nine states that allows for this exception usually requires a number of steps be followed before a person can be required against or without their consent to have the test.

As an example, in Ohio, in order to justify testing of another without that person's consent when there has been a significant exposure in the workplace, the person who was exposed potentially to HIV infection must swear to the following: While rendering health emergency care, the plaintiff sustains significant exposure; that the plaintiff has reason to believe that the defendant may indeed be infected; that the plaintiff has made reasonable attempts to have the defendant submit to a test; and that within seven days after the exposure the plaintiff himself took an HIV test and received counseling.

CHAIRMAN ALLEN: Excuse me. One more minute.

DR. CAULEY: Let's move ahead, then, to states which have authorized or mandatory tests in the special populations. This is the legislation that gets the most precedent. I want to just quickly review.

In terms of mandatory testing which very few states have actually included, the most restrictive have been Alabama, Georgia, Idaho, Nevada, North Dakota, Utah and Wyoming. In fact, in those states, legislation has been passed mandating testing for all individuals in prison or state county or penal institutions.

There are states who authorize testing for prisoners, and a number of states that have specific conditions for testing prisoners.

In terms of testing persons accused of sexual or drug-related offenses, there are in fact seven states that mandate testing for persons charged or convicted for sexual offenses, and there are four states that require mandatory testing of persons convicted in drug-related crimes.

The other populations, to note very briefly, are people applying for marriage licenses. Most of you are familiar with the statistics in Illinois, that in a year requiring marriage license testing, over 160,000 people were tested, and they came up with 23 cases of HIV infection. The only three states to actually have premarital testing were Illinois, Louisiana and Texas, and the laws in Louisiana and Texas have been repealed.

I would like to refer you to page 12 in my written remarks which identifies the specific state legislation in reference to discrimination. I will just conclude by suggesting that in the higher prevalent states, the trend is relatively consistent. Take California, as an example. The first legislation in California was in reference to assuring voluntary confidential testing followed by testing of all blood and organ kinds of donations. And then, very quickly after that, the focus in California was on testing without consent occasionally and with consent for minors.

In 1988, California legislation was primarily around whether or not authorized and mandatory testing of special populations such as persons convicted of sexual offenses. And my final point being that in 1989, California law has focused primarily on discrimination provisions, the assistance of counseling both pre and post during a test, and making sure that people have at hand access to voluntary testing with confidential and anonymous options, so that if you look in the states who have not yet begun developing legislation, we find that those are some of the patterns that they follow with those priorities.

I will be happy to respond to questions at a time when we are not interrupted so rudely by the fire department.

MR. LEVI: I guess I'm a little confused because I saw it in your paper and now I don't remember whether you said it. You talked about states that do have reporting allowing continuation of anonymous testing --

(Pause off the record due to fire alarm.)

CHAIRMAN ALLEN: Let's take a break and we'll come back.

(Recessed at 11:50 a.m.)

(Resumed at 12:00 noon).

CHAIRMAN ALLEN: Our next presenter is going to be Ms. Marie St. Cyr. We are going to move everything down from the agenda and have the challenge of testing in different populations. Marie is going to come and share with us. Then we'll move right into the programs in Public Health Service.

Again, due to the time constraints, about ten minutes and then questions and answers.

MS. ST. CYR: I wish to state that ten minutes is unfair, but I will try to keep it to ten minutes.

HIV testing as a matter of the policy in public health strategy of prevention has been and continues to be an issue since the early days. Beyond the broad issues of voluntary versus mandatory testing, the efficacy and accuracy of testing, the effectiveness in prevention of testing, today HIV testing for us is a bit of concern as the providers as the medical world move to qualify AIDS as a chronic illness and looking to long-term cures. The fact that we speak of special population may be indicative of how health and social services have dealt with peoples' concern historically, and AIDS is no different.

The epidemiology of AIDS has fostered focus on groups. In my AIDS experience working with the Haitian Coalition on AIDS, we face different populations defined by ethnicity, migration, historical antecedents and impact of HIV categorization. The scope of the problem was surely different.

Currently, my work with the Women And AIDS Resource Network has me exposed to women and children and their families, and the parameters there are gender, social perception, selfperception, historical as well, in terms of the epidemiology of AIDS, which did not show among women in the early years, and has then allowed for women to feel that they are excluded and the denial on women persists.

Unfortunately, we are still looking at women as different groups. Today, the woman in this Resource Network is working with AIDS counseling and education, ACE, a program of women and children impacting on HIV in women's lives. It is against this very general background and brief background that I will list some of the factors in testing which we have looked at.

In populations that have fallen under the so-called Amnesty Immigration Law of the 1980s, these immigration laws have allowed for testing without and sometimes with minimal counseling to the populations which are the least prepared to cope with HIV positive testing, and this includes Latin populations. They are the least prepared to cope with HIV positive testing. When recently, that have gone through a physical and medical testing for HIV because of immigration procedures, the population that we see has limited understanding of the test, limited understanding of the result. They are usually looking for a death sentence, and their concerns are mentally focused on obtaining residency and surviving as residents in the United States.

Their fear of deportation, coupled with language barriers and other social factors in their own communities, further hinder their ability to cope and deal with an HIV positive test. Your communities which are disenfranchised are attempting to deal with this issue with very limited support and funding.

Testing attached to this population is actually a hindrance to treatment. As an example, I will unfortunately select some of the worst examples to make an impact on you. One of the cases that I have worked with in which a couple and a child had to be tested for residency, that is the woman was tested first, she was positive. That positive result has resulted in her abandoning her child and her family, not to be seen for over a year. Later this partner of hers was also tested and tested positive and committed suicide in the basement of where they live.

I want to impress on you that there is a serious impact on those peoples' lives, and that we need to be more considerate of the factors of testing in a hurry, in a rush.

In terms of the women's population, in recent months agencies like ourselves and agencies around the nation have supported testing, although they had not done so in earlier years. The overwhelming majority of women we work with are coming from communities which are impoverished. They provide limited access to adequate medical care and to adequate support, as well as psychosocial support, such as drug treatment to the populations that are getting tested.

The AIDS agencies which attempt to serve these women are in a large part supported by AIDS Institute. And I want to tell you on the average of 30 agencies funded in the minority community in New York City in 1989, the average funding was $66,000 for these minority communities. I can tell you in New York, $66,000 cannot cut the needs for HIV support staff as well as material and space.

The level of funding to the minority group is simply insufficient to allow for the adequate education and service as well as reward and knowledge of HIV, as well as HIV testing in particular.

For the women's population, it's only in the last two years that we have targeted education, and the denial persists among the population. There is an urgent need to intensify outreach education and to allow for small group discussion where the implication for families in terms of testing can be discussed.

I think that testing is not justified for these populations for which I have spoken without increased accesibility and availability not only to AIDS related studies and trials but to primary medical care.

I want to give you another example. Among the women we have currently at least five women who are self-identified as participating in trial studies, who have stopped taking their medication, including AZT. Although we have in counsel discussed the impact of stopping taking medication with the clients, they declined to reveal this information to medical doctors advising them in their trials. In the trials they received the best possible medical care they can have access to, and they do not want to jeopardize that. That has some impact for scientific research data studies. I think that needs to be considered in a population where people feel that the last resort is to stop taking their medication, and we need to look at what is existing in those communities.

Psychosocial support is also not there. The established mental health services have not embraced the HIV impact on the mental health of the poor population, or the implication for those who have tested positive. In our population, there is an average number of 2.7 children among the 100 that we are serving, and that amounts to about 300 children. Many of them will later become orphaned.

Many of them are going to become orphans. I think we need to look at this particular impact in terms of the vicious cycle of drug use in a communities where adolescents who have no support to cope with knowing that they may lose a parent, that they are going to live with the HIV illness, where one member is positive and the other member is not.

And our concern is what happened with disclosure, what happened with counseling when a woman or a man does not want to disclose to the partner with whom they are sexually active, and especially when they are asymptomatic of their HIV testing. It points to the need for HIV counselor training to incorporate the many factors impacted on the lives of those tested. And also we take into consideration the length of time of the process of pre- and post-test counseling.

I think that the prison population with whom we are working now presents some major concerns in terms of confidentiality and anonymity of testing. The lack of adequate service in the system is well-documented. In our special project where we are providing professional support and peer training for 40 women to work at the facility for women, which orients and moves 1200 women per year and has an increase of Latin women, an increase of black women, due to drug-related criminal activities. We are very concerned that they, as well, as we receive information on HIV and living with AIDS and better therapies. There is an increased concern for women who want to be tested, whether there is confidentiality and anonymity.

I think I would be remiss if I didn't mention the homeless population. This is around 30,000, and I'm sure you have seen the numbers mushroom in your own communities. In our city, we are talking about the possibility of over 20 percent of that population already HIV infected. That problem for us at this point, we have no true solution to deal with the issues of testing for that population and service for that population.

In conclusion, I'm sure that you heard in the first presentation the benefits of testing and the efficiency and efficacy of tests available. What I have tried to speak on very briefly and to use some live examples is the need to put in place adequate and appropriate services to support testing outcomes. Whether testing is positive or negative, services to reinforce preventative strategies and to support persons living with HIV are essential; yet, they are sorely lacking in the communities most impacted, yet, with the least resource availability to sustain the brunt of HIV in our lives.

CHAIRMAN ALLEN: This is clearly going to be an issue we are going to deal with in the round table. If there is a pressing question that you need to ask at this very moment, we can go with at least one.

MR. DALTON: There is another category of questions which have broader applicability. One question, I just want clarification. You mentioned that in New York the average funding for minority service representation is $66,000. Was that from all sources?

MS. ST. CYR: From the New York State ~~City~~ AIDS Institute, which funded 30 agencies at the close of 1989, and the average funding was $66,000.

CHAIRMAN ALLEN: Any others at this point? We will certainly return to this very important issue here in the round table.

Thank you very much.

Next we have Doctor Hinman.

DR. HINMAN: I am pleased to be here to talk a little bit about some of our activities, specifically with relation to counseling and testing. But I also wanted to talk a little bit about the National AIDS Information and Education Program.

I should say that in the absence of specific preventive measures such as vaccines or cures, at the present time some of our most effective means of intervention are education, education including school-based education, mass media types of public information, dealing with groups of individuals who are at increased risk, and then individual education on a one-to-one basis.

I have put around a handout that on the the top of which just summarizes the level of funding through the Centers for Disease Control for major categories of activities in fiscal 1989, and you'll see that 35 and a half million dollars was devoted to school-based education, 35 million dollars to public education.

I would like to now spend a couple of minutes talking about the proposed themes for the 1990 "America Responds To AIDS" public information program, which is carried out by the National AIDS Information and Education Program.

At present, the proposed concepts, the draft public service announcement materials and messages are undergoing a broad review and audience testing with focus groups. The messages are being tested on more than five thousand persons from multicultural audiences and the general public. The plan is to release the materials in approximately June of this year.

The three primary objectives of this phase of the campaign are to improve understanding of the relationship between HIV and AIDS; that is, HIV as the virus infection of which may lead to AIDS subsequently; to the increased risk, and, therefore, the appropriateness of adopting preventive behavior, and to increase the willingness of persons at risk to be tested for HIV antibodies.

The primary messages to be portrayed are, one, the HIV is the virus that causes AIDS; two, you can't tell by looking at someone if they have HIV infection; three, many people with HIV infection didn't think that they would get it; four, persons who believe they may be at risk of HIV infection should be tested; five, there is no cure for AIDS, but early diagnosis and treatment can delay the onset of complications; and, six, that people with HIV infection can continue to be productive employees and pose no risk to their co-workers.

The standard TV/radio print ad and poster public service announcements will be developed and used with increasing emphasis on localization for high risk audiences. There will be increased emphasis on encouraging work site education programs and the adoption of employee policies, and information and materials will be developed on risk assessment, the spectrum of HIV infection, and HIV prevention in the workplace. And that is basically a summary of what is intended for the coming way of "America Responds to AIDS".

I would like now to move on to talk about counseling, testing, referral, and ~~department~~ partner notification, which we tend to think of sort of together. And the counseling part of counseling and testing represents an intense opportunity for education about behavior modification. It has many of the limitations that have been described before. It may be one time or two time, pre-test and post-test time, at a time when persons are thinking about other things as well. But it does represent one relatively intense opportunity for education.

The referral part of counseling, testing, and partner notification means referral for support services and follow-up, and may be currently the least developed part of the program. Partner notification represents the most highly focused outreach activity available. It represents direct outreach to individuals who are at direct risk as a result of having been exposed personally to HIV infection.

I would like to just summarize a few of the data that are in the handout. If we just go to about the third page or so of the handout, you will see that the total number of reported test sites has increased from January 1988 from a total at that time of 1,691 test sites to more than 5,000 test sites in September of 1989. Of these, nearly 30 percent were what we call HIV counseling and test sites, what used to be called alternate test sites, primarily carrying out anonymous testing.

The remainder of the test sites in public health facilities represent the provision of testing in sites such as STD clinics, family planning clinics, prenatal clinics, et cetera.

If you look at the pie chart that comes next, you will see that in the 12-month period, July 1988 through June 1989, HIV counseling and test sites, the alternate test sites, represented about 40 percent of all the tests carried out in publicly supported HIV testing facilities. STD represented the next largest category with 25 percent. And you can see the other categories in the rest of the pie chart.

The next three graphs just show the trends over time over the seven quarters from January of 1988 through September of 1989, and the number of tests recorded from different sites. The thing to notice on the first chart is that the number of tests recorded from HIV counseling and testing sites has remained relatively constant over that period; whereas, the number of tests reported from STD clinics has been increasing.

Similarly, in the next two charts, you see for family planning and prenatal clinics, drug, that the number of tests have been increasing progressively. The next chart which just shows two straight lines, demonstrates the trend of the percent of all tests done which are being performed in HIV counseling and testing sites versus STD clinics. What you see here is a reflection of the extension of HIV counseling and testing into sites where people are coming for services which indicate that they may be at increased risk but are not coming specifically for an HIV test.

The next graph demonstrates the number of tests performed in publicly funded sites going back to the beginning of the program in 1985 and the number of positives. And we have had approximately 2.5 million tests performed reported to us as being performed in publicly funded test sites, and nearly 150,000 of these have been positive. These are tests, not people.

I should point out that if one makes, attempts to make a correction for persons who have repeat testing based on information from a few states, we come to an estimate that approximately two million persons have been tested in publicly funded counseling and testing sites, and somewhere on the order of 125,000 to 145,000 persons have been found to be infected.

Now, if we then take an estimate of the pool of infected individuals in the United States as being approximately one million, and based on data from Colorado which indicate that something on the order of 20 percent of infected persons are aware of their infection, this would mean that somewhere on the order of 200,000 persons nationwide are aware of HIV infection, then the estimate is that something on the order of 70 percent of all the persons in the United States who are aware of their infection status learned of it through publicly funded counseling and testing sites.

I would now just like to show very briefly the next table demonstrates the number of tests performed over the seven quarters from January of 1988, which is when we began to get the detailed information, through September of 1989, demonstrates the number of tests performed by site, the number which were positive, the percent positivity of the tests that were performed, the percent of all tests that were performed that came from that type of site, and the percent of all positives that came from that type of site. So, for example, alternate test sites accounted for about 40 percent of all tests performed in that period, but about 50 percent of all positives.

The next table demonstrates, first of all, an error in the label. It should be by type of risk exposure on the second line of the table in the table. And it demonstrates for persons who describe themselves as being heterosexuals and having some known risk, how many tests were performed. And this is about 44 percent of all tests, and about 15 percent of all positives.

Other is the category of persons who

describe themselves as being heterosexual but do not describe any other risk activity. This may be because they do not wish to indicate what their risk is, or it may be that they are the worried well. I think if you look at the positivity rate for this population, for this group, at 2.3 percent, you've come very clearly to the idea that these are not just the worried well, but they include persons who are not telling what their risk is.

Then the other categories, as you see, are men who have sex with men, IV drug users, et cetera.

The bar chart then shows for each of these risk categories the percent of all tests on the darker bar that are reflected in this risk group, and then the percent of all positives. So, taking the second one in, for example, men who have sex with men account for 13 or 14 percent of all tests, but about 45 percent of all positives.

The next bar chart just shows the positivity rate by risk group and shows the highest positivity rate is men who have sex with men and are also IV drug users at about 17 percent. There then follow a couple of maps that show by state the percent positivity among groups who describe themselves as being at various risk.

And then there are a couple of pie charts and a bar chart that demonstrates the positivity rates by subgroup in those who are categorized as heterosexuals with risk. And the thing to notice here is that more than 11 percent of those who say that their risk is that their partner is positive were found to be positive. This is one of the highest percent positivity rates that we find around the country.

The handout then concludes with information about the race and ethnicity of persons who were tested. For example, 56 percent of tests were performed in whites, 32 percent in blacks, 9 percent in Hispanics, and then there are a couple of bar charts that compare the proportion of each race and ethnic group in the general population in the left-hand bar and the percent of all tests that were performed in the right-hand bar.

The next chart, the percent of the general population in that race ethnic group and the percent of all positives in that race ethnic group.

A pie chart, and then a bar chart showing sex breakdown, approximately 55 percent of all tests were performed in males and 45 percent in females. The number of positives was much higher than the proportioned positive in males as females. Then finally a chart showing the age distribution of tests and of positives.

Thank you very much.

CHAIRMAN ALLEN: We have time for a few questions, Don and then Jeff.

MR. GOLDMAN: One of your charts on the number and percent of HIV tests or positive tests by type of ethnic site. Where do you get the data to determine how many HIV tests are done by private physicians?

DR. HINMAN: These are tests reported to us as having been done by private physicians. And they represent a substantial estimate of the total number of tests actually being performed in private physician settings.

MR. GOLDMAN: Under what circumstances would a private physician report a negative test to the Public Health Service?

DR. HINMAN: This might be if the test was actually carried out by a laboratory and the laboratory was reporting a number of tests they performed, and the positives, according to the type of person submitting the specimen.

MS. AFFOUMADO: Which is the case in New York.

MR. GOLDMAN: How about if it's done in a hospital?

MS. AFFOUMADO: Everything goes to the Department of Health and Welfare.

DR. HINMAN: There is considerable variation around the country. I would say the majority of states, the majority of tests carried out through private physicians are not reported.

MR. GOLDMAN: The subsequent charts, you have in terms of risk groups and positivity, things like that, are those based upon the gross numbers? Are those also, the January 1988, September 1989 based upon the same data?

DR. HINMAN: Most of them are. There are a couple of charts which detect only a 12-month period. I think those are fairly well labeled. But most of the data reflect the complete periods that we were getting detailed information, which began in January of 1988, and the most recent reporting period for which we have complete reporting data, which is September 1989.

MR. GOLDMAN: Do you have any data which would indicate any substantial differences either in the types of risk groups, risk exposure groups, with positivity versus being seen or being tested at the alternate test sites as opposed to all of the other things?

DR. HINMAN: At present, we do not at the national level because we are getting data in a summary format.

I should say, first of all, that the data I presented to you we've only been able to collect for the last year and a half or so. It took us awhile to get the approval of the report forms. The data represents the summary of data we have developed a form which is machine seek scannable, which will enable us to do that kind of cross analysis. But at the moment, I cannot.

MR. LEVI: Fortunately, Don asked a couple of my questions so I can appear to be brief when I hadn't intended to be. I would just point out for the record that the hundred million dollars in fiscal 1989 for counseling, testing, and partner notification and fiscal 1990 is under, and I think the fiscal 1991 request is somewhere around 150 million dollars. I think given the cost about 150 million dollars will identify 64,000 who are positive, I think this is something for our discussion later as to what the given real cost given the increased demand for testing is going to be to identify for early intervention.

As part of the counseling, testing and partner notification money, I have three related questions. Does the CDC permit states to implement these programs, to also pay for T-cell testing as part of their counseling and testing money? Does it permit the states to use this as part of the process for drugs that are related to an identification of someone who is seropositive and possibly in need of intervention as the CDC does permit states, or as part of the protocol is for other STDs, like syphilis, you identify someone who is positive and needs treatment, you give them the treatment, which I don't believe is the case for HIV.

The third related question is, is there a breakdown, all the money for counseling, testings and partner notification is clumped together, is there a breakdown as to how many of those, say the hundred million dollars in fiscal 1989, is there any accounting for how much of the money went for counseling, how much of the money went for testing and how much of it went to partner notification?

DR. HINMAN: I'll take the questions in reverse order. No, I cannot tell you exactly how much was spent on counseling versus how much on tests.

MR. LEVI: Or how much was spent on partner notification?

DR. HINMAN: It may be possible to separate that out. I don't have that with me. With respect to whether we provide support for related follow-up activities, particularly T-cell testing and medications, I would point out that in fact the CDC funds do not pay for penicillin to treat syphilis. That is provided using state and --

MR. LEVI: But it's part of a protocol. The CDC pays for the testing and identification with the understanding that the states are going to provide the penicillin.

DR. HINMAN: We do provide support in some states currently for follow-up. And this is, as I pointed out earlier, a referral and follow-up part is the least well-developed part of the overall prevention program. But, in California, for example, federal funds are being used in the prevention treatment centers, as Francis described in one of the articles --

MR. LEVI: But a state under one of those cooperative agreements for counseling, testing and partner notification, if a state said we want to spend some of that testing money for T-cells, what is CDC's response?

DR. HINMAN: We do not have an automatic no response. We do not have an automatic yes response.

MR. LEVI: Because the District of Columbia was told no when they asked for that.

DR. HINMAN: I wasn't present in the discussion. The general approach, however, is that although there has been some increase in funding to support prevention activities given increased cost of doing business and increasing demands for services, one has to look at what you're going to drop if you you're going to add something else. And I think the question of whether to add a new service is one that often may get less priority.

Is that responsive to all three? I think I may have left out the first question.

MR. LEVI: No.

CHAIRMAN ALLEN: Eunice?

MS. DIAZ: Alan, did you have any data to indicate what led people either to ATSs or the other HIV testing sites, being that CDC puts a lot of money into education of communities, what some of this flushed out to, say, the people that went into ATS sites mainly heard an advertisement or something via television-funded programs?

DR. HINMAN: By and large, the people who go to the HIV alternate test sites go there specifically because they are concerned about the possibility of HIV infection. They have heard about HIV infection and the availability of testing from one place or another, and they make a conscious decision to go and discuss HIV.

MS. DIAZ: How did they hear about it, is my point?

DR. HINMAN: There are some data which I do not have in my mind.

MS. DIAZ: Do you have a feeling? Was it mainly through public messages, or referral from a buddy?

DR. HINMAN: I think by and large it's more direct contact with individuals or with smaller groups rather than mass media.

It should be pointed out that the mass education approaches have not typically focused on encouraging people to go get tested. But in terms of the other testing sites, those are sites where people are not going specifically to receive HIV testing. They are going for another reason. They are going for an STD, family planning services, or they are going for HIV drug treatment.

CHAIRMAN ALLEN: We are really getting at the heart of what we are going to be dealing with this afternoon. What I would like is to ask the questions. Maureen is going to record the questions to make sure they are not lost in the shuffle of the round table. Don had a question. If you could ask the question at this moment.

MR. GOLDMAN: It can be a yes or no. The answer that you just gave to Eunice, is that based upon empirical data or based upon your best assumptions, understandings and your best guess based upon the circumstances?

DR. HINMAN: Which answer? I answered two questions. One which related to why do people go to alternate test sites, and I said I believe there are data on the subject. I do not have them in my mind.

With respect to the other facilities, I can tell you with confidence that this is the introduction of offering testing in sites where people are coming for other reasons.

MS. AFFOUMADO: I actually just have a statement and I think we'll get into this later. I want to be very clear that people understand that the models of medical care in the management of HIV are not the same as STD. We need to really talk later on about what proper treatments are and what the implications are for T-cell testing. I want to bring that up.

DR. HINMAN: Probably the medical model for TB is closer to that for HIV. It is not the same, but it is perhaps closer in that it does involve long contacts.

CHAIRMAN ALLEN: This will be something we will need to bring up later. I appreciate your bringing that up, and we can talk about it in the broader context of all the participants. It's frustrating at this time because we can't all just jump in because of time restraint.

Peter, if you want to ask a question, if it's not a yes or no --

MR. SANCHEZ: It would seem that

based upon the data that you supplied and the graphs, you need to apply to people who tend to go to areas -- that has great implications. That is my interpretation. I hope we bring that up.

DR. HINMAN: I would respond to that only by saying that we have little information to indicate that a substantial number of the tests being performed, say, at STD clinics, are being performed because people are specifically going there to get an HIV test. They are primarily being performed for people who go there for STD examination or treatment and are offered the possibility of HIV testing.

DR. O'NEILL: Let me say I think it's particularly appropriate that I follow Doctor Hinman with my comments about HRSA's activities vis-a-vis early intervention. I would first like to express that Doctor Sam Methany (phonetic), who is the Associate Administrator, was unable to attend this meeting and asked me to fill in for him. I think that it's important for you to know.

First of all, to give you a little oversight, HRSA is a large agency, three bureaus. I work in one of those bureaus as the Medical Director of their HIV program, and I am most familiar with those particular programs. I have been briefed quickly and rapidly on the other programs within HRSA that have to do with early intervention, and I will confess that it's kind of like drinking water out of a fire hose in terms of really having a completely firm handle on all of the statistics you may need. I am saying this up front because I will be very pleased to supply you with any information in written form that I am unable to do in oral form as I do this.

I think during the course of our afternoon stay we will perhaps be coming to a better understanding ourselves of what early intervention in AIDS and I should say in HIV infection means. Certainly our view is that it includes prevention, education, psychosocial support, and medical intervention now as well for certain groups of people. HRSA's mission is to support the delivery of health services to disadvantaged and certain populations and to develop national health resources of health professionals and facilities.

I want to make it a point with regard to early intervention that within HRSA, although we do have some very specific HIV-related programs, in fact we even have certain proponents of those programs or certain projects funded by this program which specifically deal with early intervention. Our real goal is to work within and stimulate and expand existing health care systems, particularly the primary health care systems, rather than to develop parallel or new systems of care for HIV positive individuals. Our challenge in doing this is to not develop a pragmatic system of care, but rather to encourage the continuity of care for anyone who is HIV positive from the time of learing of their infection to whatever the later stages of that disease may be.

Our mission at HRSA with regard to HIV is diverse. We encompass primary psychosocial support, education, and several other areas. I want to stress that in terms of our response, we have tried very hard to respond to service needs as defined by communities. Particularly, in the service demonstration programs, which is one of the programs with which I work, we have made it a cornerstone of our program to try to learn from communities what needs are, where the gaps are, and how we may best stimulate and fill them.

Let me say a few general comments about the specific mission of HRSA as it relates to early intervention in HIV, and then I will go on to describe some particular programs for you.

HRSA has no one program that is specifically focused on early intervention. But the very nature of our HIV programs, however, HRSA is supporting early intervention in several areas; service demonstration projects, for example. A study that we have between January and June of 1989 provided services for over 21,000 individuals who did not have a diagnosis of AIDS. HRSA is comprised of three bureaus, as I mentioned. The Bureau of Health Care Delivery and Assistance operates the community and health center's program. Through this program over 600 health care centers are supported, of which nationwide see about 5 and a half million people.

These centers traditionally serve medically underserved populations, which are not disproportionately affected by HIV. In 1989, our studies show that 67 percent of these centers did provide HIV screening. The Bureau of Health Care Delivery and Assistance in their studies have indicated that in some areas up to 3 percent of users of these clients are HIV positive. In some states, the bureau estimates that their clinics see a significant portion of all HIV infected individuals in that state.

For example, they estimate that within New York State 10 percent of HIV infected individuals are seen through these clinics, 12 percent in Maryland, 18 percent in Pennsylvania.

There are several specific programs within this bureau that relate to early intervention in HIV. First, there is a joint effort with the Centers For Disease Control to develop HIV prevention and activities and to strengthen them within the community health centers. This has been a pilot project involving three centers in Miami, Bronx, and Newark. Over a three-year period, through a collaborative effort between our agency and the Centers For Disease Control, four and a half million dollars has been, well, it's a one and a half million dollars per year program, which is an effort to tie in counseling and testing around HIV with services provided at these three centers.

Recently, the community health center's efforts have been augmented with 10.8 million dollars appropriation, which will be awarded as grants to a number of community health centers. The goal of this program will be to augment the ability of the centers to care for the entire spectrum of HIV disease in the population which they currently serve. These will, of course, include asymptomatic seropositive individuals.

It is important to note that this program, however, is designed to help these needs in areas that are highly effective, but it is clearly expected that all community health centers will be involved to provide care for the HIV positive person regardless of whether they are a recipient of one of these grants or not.

The third program to mention are the National Institute of Drug Abuse and Bureau of

Health Care Delivery and Assistance Demonstration Projects, which is a 9 million dollar series of grants awarded at the end of fiscal year 1989 to 21 entities. These were state, local health departments, private and non-profit community centers. The specific point of these programs was to develop linkages between substance abuse treatment and primary care activities.

Let me move on, as I've just been told I have 120 seconds left, to the Service Demonstration Programs. These were HRSA's first specific programs related to HIV. They were begun in four sites, New York, Los Angeles, San Francisco and Miami, and there are now 25 sites in this program. The major purpose of the Service Demonstration Project is to support the organization of systems of care by developing coalitions and service providers in community organizations, to identify gaps in service needs, to demonstrate how to meet these needs.

I think the point is that when we talk about early intervention, this is becoming increasingly one of the gaps that is being identified in the communities that we are attempting to respond to within the Service Demonstration Project program. The Service Demonstration Project program has always had a major emphasis on providing continuity of care, and the structure of the program does allow the ability to respond to this identified gap of needs of the people that are early on in the stages of HIV infection.

Let me just mention two examples of early intervention activities that are ongoing in the Service Demonstration Program. I'll mention three, actually. One of them that is closest to my heart is the Seattle County. I mentioned before I came to work for the Public Health Service I was a primary care provider at the County Medical Center in Seattle. And the nurse practitioner who worked with us and provided a tremendous continuity component to the care provided to that clinic was partially funded through the HRSA demonstration project in Seattle county.

West Hollywood and Los Angeles, which was also funded with service demonstration dollars, provides medical monitoring to asymptomatic seropositives. The Fenway Clinic here in Boston has several components which are funded by service demonstration dollars. The Dimmock Community Health Center uses service demonstration funds for providing education, HIV support groups, particularly for minority women. The Treatment Center at Fenway Clinic employs a nurse practitioner salaried by the demonstration program as director of that operation. This center, for example, provides an inhaled Aerosolized Pentamadine program and therapies.

We have other programs at Health Service Planning Program, which certainly emphasizes the needs of early intervention. Finally, let me just mention that in 1989 and 1980, a total of 73 million dollars was appropriated to help individuals to acquire drugs which would, which are appropriate for use in AIDS care or HIV care. The original criteria when this program first started was that the money be used for drugs which had been shown to prolong the lives of persons with AIDS.

Since that time, the language has been liberalized to state that the monies may be used to purchase drugs or to help in the purchase of drugs for which not only have been shown to prolong life, but which have been shown to prevent serious deterioration in health. That right there is an expansion of the ability of states to use these monies to purchase drugs earlier on in the spectrum of disease.

The AIDS Educational Training Center Program, which is our initiative to support education to public professionals and HIV disease has also of late had an increasingly strong emphasis on early intervention.

I would in closing note that I was asked and conducted a two-day seminar for the regional, two months ago, specifically on the topic of early intervention to educate the HTCCs about what their mission should be.

Finally, I must make one personal plea or personal statement that comes not out of my role as a bureaucrat but really from another life when I was taking care of patients and working as an HIV testing counselor. I think that, and I'm sure we'll talk about this in the future, but the roles of reimbursement for services and the issue of discrimination and confidentiality are extremely key when we talk about trying to meet the overall needs that are raised by the question of providing early intervention services for those who are HIV positive.

Thank you.

CHAIRMAN ALLEN: Any quick questions?

MS. AFFOUMADO: Just another observation, again for future discussion. In listening to you talk, you talk about the HRSA funding, continuity of care, in terms of diagnosis and treatment, but consistent with the admissions of the clinics to provide comprehensive and coordinated clinics for people.

In New York State recently there was an announcement of a Medicaid reimbursement rate for community-based clinics of which many of them are 330s in New York State which are providing services to communities for HIV infection, which allows a reimbursement rate only for early diagnosis treatment for asymptomatic patients. I think there is a real issue when you talk about reimbursement where a state or a local locality may be setting reimbursement for funding according to certain parameters and criteria and the Feds and HRSA and Public Health Service may also be doing it in another way and then these clinics get caught in the middle because clearly funding and reimbursement levels are driving the way we take care of these patients unfortunately.

So we may want to look at the inconsistencies between the various governmental entities in terms of especially Medicaid because Medicaid is really the primary reimbursement mechanism for this population.

CHAIRMAN ALLEN: I would like to make one statement. We do need to close. But one of the concerns that I have is that HRSA seems to be losing its funding in the area of the AZT, the home care, and other crucial areas, demonstration grants, and so forth. At the same time, we are looking at increasing the advertising for early intervention.

I think that's something we need to look at at the round table as to what's happening here and the inconsistencies and where does that leave the individual and the CBOs. So I leave that to the next hour. And we will return in an hour.

(Recessed for lunch at one o'clock p.m.)

AFTERNOON SESSION

(Resumed at 2:10 p.m.)

CHAIRMAN ALLEN: Mark, do you want to go ahead and start the whole process?

DR. ROBERTS: Good afternoon. Welcome to Boston those of you who have come from sunnier climates. I'm really delighted on behalf of the local Chamber of Commerce and Mr. Wright and any other natives to welcome you to Boston.

I was asked by the working group to be the facilitator for this afternoon's, I think, square table as opposed to round table conversation. Let me say a word or two about what I see my role as and some ground rules. Then we'll just zoom right into it.

My job is to help Commissioners who are scattered artfully among you with no apparent plan or order, help the Commissioners have a conversation with all of you that serves their objectives. And I just want to say that I view myself as sort of their instrument in this situation. And, to some extent, if I seem to treat them a little better than I treat some of you, it's nothing personal. But it is really, in some sense, an alternative to what would be a more conventional hearing process in which there would be even more control. So that's the first thing I want to say.

Second thing is that it is hard in a public meeting, particularly in such a grand and elegant setting, to have a really effective and blunt exchange, but I think that's everybody's objective here. These are really hard problems. You know far better than I. None of us will be well-served if we don't really try to say what's really on our minds and really help them think about how hard the problems are.

There's no sense that we will necessarily force any consensus or agreement. It's not one person, one vote. No show of hands. There are only a few people in the room who get to vote. Most of us are not among them. But we're really here to share our best thinking with them and help them understand the problem.

We thought that, and I will try episodically at the risk of knocking our court reporter over as I scoot in and out of this narrow passage, I'll try to keep track of at least some of the comments on the flip chart as we go. The logistics of this are a little complicated about how we do this, and I'm afraid I'm going to have my back to you guys a little more than I otherwise might, and I apologize in advance.

We just had an elegant lunch at The Bistro that Larry Kessler recommended. It was the view of the working group members that they would like us to begin with the issue of testing, which is in part what this meeting is about: Who do we test? When do we test them? How do we test them? How does that answer vary with different kinds of client groups and different kinds of circumstances, different political and geographic circumstances? We'll start with that.

Then as a sort of second move, we want to begin to talk about what else we think needs to be present in order to make various kinds of testing strategies sensible and appropriate, about service context within which service needs to be embedded.

And then if the first half of our conversation is going to be about ideals, then the second half is going to be more about realities and what's the difference between where, what package of activities and programs and services seems desirable and the stuff that's actually out there in the world. We have around the table enormous expertise from a variety of front lines that can tell us what it's like out there on those front lines.

Scott, does that seem reasonable to you, a summary of where we were?

CHAIRMAN ALLEN: Yes.

DR. ROBERTS: I should ask who would like to start us off? And let me say one other thing. The acoustics in this room are really lousy. So please speak loudly because otherwise you are not going to be heard.

Who would like to open this up on the who and when? We don't need a comprehensive answer, but why don't you start with, from your point of view, the clearest argument, the group that is most desirable, and in what way, voluntary, routine, anonymous, confidential, if you could pick one kind of testing program, what would you pick.

Peter? And, by the way, one other ground rule. I don't actually know any of you, and I'm going to presume we're all old friends and we're going to be on a first name basis. I hope that doesn't offend any of you, but I'll do it anyway.

DR. SMITH: Starting from the premises that generally testing leads to a step, and usually a therapeutic step, I would generally say the premise issue goes to those who would benefit from the testing.

In other words, if you live in an area where there is actually possibilities of treatment and those people are most likely to benefit from treatment should be tested.

CHAIRMAN ALLEN: Who would that be?

DR. SMITH: Those that stand a high probability of having been infected with the HIV virus should be tested. I think it's real hard to seek a lot of specific groups without getting into cliches, but I do think that what has hampered the AIDS effort a lot is the fact that we provided a lot of testing without having much to do with it.

DR. NOVICK: A very important issue here about who is if indeed we identify who, how do we tell them that they should be tested? I represent in my community a population of people who don't hear our voices at all because they do not have primary care and they don't trust those who speak; that is, they don't have trust, certainly, for white people who speak.

And so part of the question of who is when we identified them as the people at high risk, how do we tell them what we believe?

DR. ROBERTS: Do you think that in some ways there's almost an inverse relationship between who we need to test and who we find it easiest to reach? Is that what I hear you saying?

DR. NOVICK: No. There are some people that are very easy to reach, the worried well straight white people. And I'm not opposed to reaching them. But for various specialized reasons, those who are at risk will not hear our voices unless we change our voices or find modalities to reach them. That's literally true. They will not hear a single word of our wisdom.

DR. HINMAN: It's true that many of those who are at highest risk are disconnected from the system, but there are many who are in the system for one or another reason, some of which is a reflection of their risky behavior: STD clinics, IV drug treatment programs, et cetera. And this is a way of directing services at a population which is at high risk, which is, at least at that moment, in contact with the system.

DR. ROBERTS: That goes to the data you presented earlier today about the relatively increasing role of these other certain clinics. What's your sense about how to do it in that regard? I mean, is this an area that we ought to be giving a lot of priority to? Expanding, testing in the already existing service system, and how does that deal with the people who are --

DR. HINMAN: With some difficulty it deals with the persons who are totally unconnected. It doesn't really deal with them. It provides, however, an opportunity to reach those who are connected to the ones who are connected to the system. For instance, partner notification. Again, the single most targeted outreach activity is to try to reach the partners, needle and sex-sharing partners of those who are infected.

DR. ROBERTS: Rona?

MS. AFFOUMADO: I have a couple of observations. The first one is I really take umbrance with the idea that we need, who do we need to test. I think that that's very dangerous.

DR. ROBERTS: What word would you suggest?

MS. AFFOUMADO: I think the real reality is similar to what Alvin is talking about, testing is not a service. We must understand clearly that HIV antibody testing is not a health care service. It is a diagnostic tool that may help in treating people and preparing treatment plans for them.

And I think we also have to understand that the kinds of services, quote, where we are providing testing, are also not true health care models. They are treatment specific models where someone goes for a particular need and gets that need and then leaves and is not plugged into a health care system.

So we have to really, what we've been doing all these years is taking this HIV antibody test and having an isolated, hanging from the ceiling on this little rope in this little center and using it for all kinds of things except for providing services.

DR. ROBERTS: So --

MS. AFFOUMADO: The who makes me a little crazy because I want to think of it as people. And when I think about the people that those who represent, especially in terms of where the services are being provided now for the testing services, those who are the most disenfranchised and the people who are not in a health care system.

DR. ROBERTS: I just want, so that we all understand because I also had the how up there. And if I understand you --

MS. AFFOUMADO: I think you should do the how first. I think the who is really --

people are important, but you have to first put together a model that really is a working model.

DR. ROBERTS: Let me, since there's obviously disagreement around the table about what that model might be, I just want to push you still further. I understand.

Let's talk about what I heard you saying was you feel very strongly about the desirability. And in a sense I hear you relating to Alvin's comment, about linking the availability of diagnostic testing to the availability of comprehensive medical care services for these disadvantaged groups.

MS. AFFOUMADO: People who are disadvantaged. There are some who are not.

DR. ROBERTS: I understand. Now, if that's the argument, again, is it your viewpoint that we all ought to worry about fixing the health care delivery system before we worry about this issue? Is that what I hear you saying?

MS. AFFOUMADO: What I'm saying to you is we are spending billions and billions of dollars on an HIV antibody test which we use for research purposes, surveillance purposes, prevalence purposes, partner notification, and we are not putting together the health care system that really is the model. You know, a test is only a test. It doesn't need anything if you don't have the services to back it up.

Education, only education, if you tell somebody that they may be infected with HIV, you just tell them that. What are they going to do with that? If they have no place to get a medical examination and get help for their psychosocial needs and medical needs, what's the point of telling them anything if you're only telling them something that's useless which they can't act on?

My feeling is that we have been using testing for everybody else's purposes but the purpose that it should really be used for as part of a comprehensive medical management model. It has created a lot of data for people who really aren't even in the direct service models.

DR. ROBERTS: Could I ask other views and reactions around the room? We have had a fairly strong and programatic comment that really has lots of implications.

DR. ST. JOHN: I get a little bit nervous when people start off by saying who are we going to test without carefully considering why.

DR. CLEARY: This morning we talked about the goals of a screening and testing program. I think it's important to distinguish different goals and they are not necessarily incompatible goals. But there is the epidemiological goal, the individual goal. If our goal is to detect all the people that need care and to be put into a medical system, that's another goal.

I think that's why it's very important to have the reason why one is testing clear in mind before you start talking about who and how and so forth.

DR. ROBERTS: And what do you think? Paul Cleary and I are old friends and colleagues on a bunch of other projects. One of the problems I had with his presentation is that if you state all possible goals, you don't necessarily sharpen the ability of the goal conversation to inform your programatic priorities, right?

So I wondered if you had any sense about -- I mean, I'll put your question back to you, if I could, which of the goals are you particularly concerned with and what do you think those implications in turn are for testing and/or care strategies? In a sense, I'm asking you to answer your own question.

DR. ST. JOHN: Among several possible goals, I would like to lump them into two major ones. One is the epidemiological ones, and that has been carried out I think rather successfully through the anonymous testing, unlinked testing of various population groups, try to monitor the spread of this disease in a population.

Then the other thing is to look at trying to identify the individuals in the population that now can benefit from some of the recent advances.

DR. ROBERTS: And what is your comment about testing as a, which I also heard this morning -- let me say, as we go on, I will take different positions, switch to all sides of the issue. Please don't try to figure out what my own views are because if I'm really successful, you won't know, or, even more important, care what my views are.

But I heard this morning somebody saying that there was also the goal of using testing as a targetting device for prevention, which -- you didn't mention that and I wonder how you feel. Alan mentioned that in terms of partner notification just a minute ago. How do you feel about that?

DR. ST. JOHN: Since prevention depends so much on individual action, I tend to sort of lump that in with the detection of the individual. I think you would like to want to identify an individual just solely to help that person. You would want to do more than that in terms of adding a prevention component, changing that person's behavior, et cetera.

DR. ROBERTS: If we wanted, we could perform a thought experiment in which we could design programs that did less for the people who were already infected and more for the people who were not, or vice versa.

DR. ST. JOHN: That's correct.

MR. SANCHEZ: I would like to support this lady's position.

DR. ROBERTS: Rona.

MR. SANCHEZ: I think it's important to look at the economic and the cultural realities in thinking about testing and the stigma that's attached to being HIV positive or even going, considering taking the HIV antibody test, and also the health care systems that are in place. I know that for many people that we service at the Commission, what they do, people of color and poor people basically go to the emergency room at the hospital. And the systems that are in place in the hospitals are inadequate, they are overcrowded, and there is an inability to deal already with the impact of the epidemic as it stands.

So I agree with what Rona is saying. People that go and take a test and test positive, where are they going to turn to? To the same clinics in their communities who are at this point many of them are unable and unwilling to deal with an HIV positive person. We experience a lot of avoidance and a lot of rejection to treat and service a person who is HIV positive. I work for the Commission on Human Rights in the AIDS Discrimination Division.

DR. ROBERTS: Marie, you had wanted to get in a minute ago.

MS. ST. CYR: I just think that the who limits prevention. When we look at the who, we fall much more quickly into the curative model. This is much more compatible with how we see medical care. For the communities that I have talked about in terms of disenfranchised and poor communities, it doesn't at all respond to the need for prevention model.

DR. ROBERTS: This is a very interesting point. In response to what I said to Ronald, I just want to push us on this, that, of course, you can target prevention in ways other than through partner notification, contact tracing, or whatever. So there are other ways to do prevention other than through testing. Do I understand?

MS. ST. CYR: Yes.

DR. ROBERTS: So are you saying that you think testing is not particularly effective, or not, should not be viewed primarily as a preventive strategies, that other preventive strategies are more important?

MS. ST. CYR: I think there needs to be a parallel approach that looks at other ways of dealing with prevention in those communities; that if we only did testing, and we're talking about discrimination, fear of disclosure, we're talking about denial, and we're asking people to test.

For one thing, there is a lack of understanding for the reason they are testing. There are many people who don't understand the treatment, or don't trust the information. So you have to have some parallel model to deal with the needs of those communities as well.

For example, if you look at the black community where we have a family focus, church focus, support, historically, then you would want to consider infusing information about HIV in these communities in such a way that it effects the whole family system, and the whole leadership in terms of the churches and the leadership, for example, like the black leadership commission on AIDS that are becoming a voice of the people.

DR. ROBERTS: So are we talking about the possibility of a community and institutional approach to prevention as opposed to just an individually oriented approach to prevention? Interesting.

MR. LEVI: I also have a problem with, and I think what it does is bring us back to the care system, but with the original question defining who should be tested as those who are at high risk --

DR. ROBERTS: I didn't define it that way.

MR. LEVI: And you started defining who would benefit those who are at high risk, which implies that you would target your efforts of people being tested to those who are at high risk.

DR. ROBERTS: That was Peter's comment just so we can blame the right victim.

MR. LEVI: The problem I have with that is there is the fundamental assumption that the system that is going to be offering the testing, which in many instances is going to be the care system, will know how to identify people who are at high risk. And if we know anything about the medical and health care profession, it is that they are particularly uncomfortable asking people about their sexual history, and particularly, and assuming they want to cope with IV drug use, they are probably equally uncomfortable asking about that, and they certainly wouldn't ask certain types of their patients because it would be an insult to ask that sort of thing.

If it's a family practitioner, the husband and wife are patients, they are not going to ask the husband about whether he engages in homosexual sex as well as heterosexual. All those issues, I think, makes it important to look, to do something that I don't want us to do yet because of other issues; and that is, if we think HIV screening is that important, should it in an ideal world be offered as routinely as women after a certain age are offered mammograms and so on.

Everyone is offered an electrocardiogram. Should that level of screening be occuring? And I don't think we are at a point where that would be acceptable or workable. But then you have to go and look at the system and say, what can we do in the system to make it that way.

DR. ROBERTS: Two comments or questions. The first one, one of the comments Paul Cleary made this morning and he passed over it very quickly, is that the ratio of false positives to true positives, I'm sure you know this as well as I did, if not better, in any screening system depends on the rate of true positives. I mean, if the false positive rate is one percent and the true positive rate is four percent, then a fifth of the apparent positives will be false. If the true positive rate is only one percent, then half the apparent positives will be false.

And when he talked about the desirability of limiting screening to high risk populations because in a sense he sees the false positives as a cost of testing and the true positives as the benefit of testing, and he wants to do testing where the costs are commensurate with the benefits. This is a fairly standard argument now, and it seems to cut against what you just said and I wondered if you would respond.

MR. LEVI: The two points I would make is fundamental to your assumption is that you are able to, you are going to know when you test someone that this person is truly high risk or not. I don't know that we can do that.

And I guess secondly on that, I would pose the second issue to John Ward, and that is once you've gone through the two ELISAs and the Western blot, are we still dealing with the general population as opposed to the high risk population, whatever that is, with those kinds of levels of false positives?

DR. ROBERTS: I heard you say the false positive rate was, what, .15 percent?

DR. WARD: You described what predictive value was in terms of it depends upon the population you're testing. I made a mention in my remarks that you always want to connect the interpretation of the lab result with what you know clinically about that individual whenever you can. It does impact on how you interpret test result. And after you finish the ELISA and you come up with the Western blot and you come up with a positive result in someone whom you've evaluated and believe to be low risk, you have to be more concerned that test to be a false positive and you want to repeat that test, versus someone coming in with conditions associated with infections of HIV.

DR. CAULEY: I wanted to follow up on Jeff's observation and make it a little more specific in that we spent the first several years of this epidemic identifying the distinctions between risk populations and risk behaviors and we made a big deal about that and talked about not identifying risk populations.

It seems to me that the shift in thinking to now talking about risk populations has to do with an expectation that if in fact we identify a risk population we are somehow going to be able to serve them medically. If in fact that is the assumption, then the shift needs to go back to Rona's comment about the health care system. If that's not the assumption, I would like to know how come we're talking risk populations.

DR. SMITH: I don't think we were talking about risk populations. I think when I said that the premise should go to those who have the most benefit, it's a functional definition, not a population definition.

In other words, if you identify behaviors that are related clearly to HIV positivity, those are the type of persons who are most likely to benefit from it.

I must also state in response to Jeff's comments that the medical profession has learned an awful lot. I mean, we --

MR. LEVI: I think we have a long, long way to the medical profession being that comfortable.

DR. ROBERTS: That is clearly always a safe claim.

DR. SMITH: We have learned an awful lot. I think that many of us, speaking for myself also, are asking the questions that you are mentioning. We are having to do this and we must do it. But I do think that now that we are really on a threshold of an era where we can do something about it, practice, intervention and comprehensive care, such as --

MS. AFFOUMADO: That's the problem. You've learned a lot, but the people you've learned a lot about can't use your knowledge because you're not going to take care of them.

DR. ROBERTS: We still have unresolved issues on the table, the issue both Alvin and Rona raised, and I offered it as a paradox, and Alvin took the one end of the spectrum but I push it back to you. That is, in some ways lots of individuals who are likely to be infected are also individuals who are not well connected with the care system. And that poses a very serious, it seems to me, strategic problem about to what extent are you trying to reach out to them through testing, and to what extent do you want to reach out to them through the care system of which testing is a part.

And the question that I heard Jeff, the point I heard Jeff say, which I wondered whether you disagreed with, Peter, is the point that says some of those historically underserved groups are for a whole variety of reasons not groups that the medical profession is rushing to serve, either because of sociological or because of financial barriers. Do you disagree?

DR. SMITH: I don't disagree with that.

MR. DALTON: This really arises out of something that Marie said this morning that I've been struggling with since then. She described a woman, I think to be a black woman, who somehow managed to find herself into a clinical trial, which is always impressive to women, who was on AZT who in fact stopped taking her AZT but continued with the program because this was her primary medical care. So if we have somebody who has found medical care not by going to a medical practitioner or even to an emergency room, which is unfortunately the primary care of choice for people in that class and race, but through a drug trial, of all things, but obviously is HIV positive and on AZT but then stops taking the AZT, I wasn't sure what you thought that was about.

The message you gave this morning was,

well, people who are conducting trials don't understand the results may be a little bit -- I was wondering whether the kind of distrust that Alvin was talking about before even extends to the point that even when people are supplied treatments, they still may not avail themselves of it?

MS. ST. CYR: There are a number of factors, I think. The primary one is that this woman feels, it's not only one woman, 5 out of 112 women that we have, feels that it is where they can get medical care with concern; that the clinical trial, persons who are working with them, take time to talk to them; that the woman feels this is where she receives good care that she needs.

The second factor is she stopped taking the medication because she says that she doesn't feel better with the medication. But she is not relating that to her medical doctors.

MR. DALTON: In other words, maybe the side effects of the medication are sufficient.

DR. ROBERTS: We do know, Harlon,

it's not at all uncommon in all ethnic and income groups for many patients not to continue on medication regimes if there are either side effects or lack of noticeable benefit. We've seen this in hypertension medication and a whole bunch of other areas.

DR. SCOTT: I would like to comment on the issue of concern about false positivities and go on and further mention what populations we can reasonably test. I am convinced from data from the armed forces and the Minnesota blood banking test systems that the risk of false positives in a very low prevalence population is extremely low. And it is very unlikely that anyone is going to have hung around their neck a false positive designation, especially when done in the context of a careful clinical evaluation.

So I think it's reasonable to offer the test to anyone. And rather than saying you are obviously, through history or behavior or whatever, a high risk person, even though sometimes that's clear, many times it's not clear. So the key about who is the person themselves that should be afforded the opportunity to have the test, based on, at a presentation as part of the overall counseling, which deals with who in fact is at high risk. What are high risk behaviors? And you, yourself, determine whether or not you want the test.

Then we can take the sting out of whether we are going after specified groups.

DR. ROBERTS: So this is similar to what Jeff was arguing, in a sense, a moment ago.

DR. SCOTT: Yes. And the test is very good. The specificity of one in a million, if you look at the Minnesota one, it's stunning, when the laboratory service is properly done.

DR. COTTON: I want to make comments that probably center around that caveat. I think that an earlier speaker distinguished between essentially testing for screening and testing for diagnostic purposes. I think clearly all of us understand that there is a tremendous difference between those two modes of testing.

The gentleman who just spoke, I'm sorry, I can't see the name plates, talked about the fact that he felt that false positives were so low that in a diagnostic setting they were acceptable. And I think with some reservations, I would say that's true.

DR. ROBERTS: What are your reservations?

DR. COTTON: First that the data that we've heard largely about the quality control of testing has indeed come from the military and places like Minnesota who have spent an extraordinary amount of care in that quality control. The military, when they set up their program, set out blinded panels of specimens to multiple laboratories, only picked those laboratories that achieved the best scores on that system, have a built-in system of quality control to make sure that those laboratories meet certain minimum standards.

I am a person who gets phone calls about false positives, and they are not, I would guess, one in a million. I think that those of us who dealt with the whole question of medical testing in other settings, be it cholesterol testing, chest x-rays, PAP smears, know that there is a tremendous diversity of quality across laboratories.

I agree, though, that in the clinical setting I have some handle on that. If I have a patient who has high risk behavior and that person has a positive ELISA confirmed by Western blot, I feel that to the extent humanly possible, that is a real result, I would believe that, I would deal with it.

In a screening setting, it's an entirely different issue. You don't have that information until you already have the test result back that you have to go out and get that information at that point.

So I think the issue of false positives and how important they are in fact depends on how you are doing the test or who is doing the test. I think that we shouldn't oversimplify that issue.

I think part of the problem we are having here this afternoon is that we are dealing with many things that are changing very rapidly. The test has become better in terms of quality control, although certainly not at the standard I think is acceptable. We have therapies that clearly are working, but I think none of us who use those therapies feel that we have made dramatic progress in terms of actually curing people. And we have an epidemic that is clearly moving in terms of who it infects. So that we are at a particular point in time.

If we had a conversation about testing two years ago, I think most of us would be saying very different things than we are saying this afternoon. I suggest that if we have this conversation in two years, we might be saying very different things. So we have to be very aware of the point in time that we are all working at, and I think clearly distinguish why we are testing isn't screening or diagnosis before we can really answer the question as to who should be tested.

DR. ROBERTS: I understand two points that I hear you making. First, the fact that things are different, the test is different, the treatment is different, the epidemiology is different. I take it it is that perception that leads to the meeting today, right? That, in some ways, as I understand it from the Commission, this issue needs to be looked at because the situation is so dynamic.

And I hear clearly a warning to all of us that anything anybody concludes about this now, they have to be prepared to reopen in another two years because it could be quite different in another two years. I think it is a helpful caveat.

I want to go back to the first part of what you said, about the difference of a clinical versus a screening context. In a sense, what I heard you saying, and correct me if I'm wrong, is that in a clinical context, you have some sense who is high risk. And it's not a high risk population; it's a high risk individual. And that, therefore, in a sense you can manage the information. And, in a sense, that's really quite parallel to what Rona was saying about the meaning of the test depends on the care system in which it's embedded.

MR. GOLDMAN: You can go on and come back to me later.

MR. DALTON: Just a short clarifying question. I thought I heard Denman say that he is quite convinced that the false positive rate in a low population is really minute. I think -- he said therefore there is no problem with testing everybody. Did you say in the low prevalence population?

DR. SCOTT: Yes, that's right. We don't have, and I don't know of anyplace where you're doing mass screening outside of a therapeutic context. I think any testing is properly done, except for the anonymous blinded epidemiological surveys in a therapeutic context so that somebody is counseled, talked to, and advised and makes that decision. But it is reasonable to talk to anybody about it, given the fact that no matter how skillful a historian in terms of sexual preference, drug use, et cetera, you might be, you still will be buffaloed many times because the issues are and always will be so sensitive.

So it is safe --

DR. ROBERTS: I see Jeff saying that's what he was saying.

MR. DALTON: I take it there is no reason to be a historian if in fact even the most low prevalence populations, you are saying the false positive rate --

DR. ROBERTS: Let's be clear about a technical fact, Harlon, because I think it's important. The absolute number of false positives is relatively independent of the prevalence rate. It is the relative number of false positives that really depends upon the prevalence rate.

MR. DALTON: But I would assume, I can't tell whether in fact Denman agrees with that, and if he does, it seems it follows that if one is not to be concerned with dealing with the low prevalence population about the relative lack of the false positive, there is even less concern with the high risk. And, therefore, all this stuff about history, from his perspective, is neither here nor there.

DR. SCOTT: Screening means double ELISA followed by the Western blot, not the single ELISA.

DR. NOVICK: I wanted to go back to goals for a moment in two ways. First, I think we probably all agree that it is an appropriate goal of testing to lead to prevention. That is what we call safer sex or safer drug use; that is, reducing transmission, or to lead to medical intervention or to develop data.

Now, having said that, I want to call to your attention historically it hasn't been associated with those goals. Frequently, the goal of testing has been to stigmatize because in many settings people haven't been given any counseling on how to preclude transmission.

For example, in the prison system, where testing has been most prevalent, counseling has been least prevalent.

And in another way, more broadly, prevention has focused not on the counselee, but on his unknown partner; that is, massive investment in partner notification and almost no investment in the client, him or herself, because the federal government and state governments are so shy about allowing specific language to be used in counseling; that is, language around condom use, around not sharing injection equipment, around seeking to gain access to sterile equipment, and other kinds of counseling that state and federal officials are very embarassed by.

So, indeed, the goals in the past have not been the ones we are talking about. So we also have to keep in mind that we want good goals now.

And my last comment is that we can achieve intervention without massive screening or other ways by developing STD clinics, prenatal clinics, other health care sources where physicians could identify by history vulnerable people and move into being individually in the health care, we certainly can develop educational prevention modalities without massive screening. We know exactly how to do that. We address our messages in a focused fashion to all the different American communities. That doesn't require screening anybody.

So we have to figure out why we want the tests. I think that brings us back to the possibility that we really wanted to stigmatize and not to facilitate.

DR. ROBERTS: So what I hear you saying to us all is that even if there is agreement around the table around what good testing would look like, that doesn't mean that the world conforms to that notion.

DR. NOVICK: It doesn't mean that it leads to what we would tend to agree upon as the goal of good testing, which is to keep people well and to keep them as well-managed if they are already ill.

MS. DIAZ: I would like to ask Alan another question. This morning when you talked about the 70 percent of people that are tested in this country coming through the public system, is that a correct figure?

DR. HINMAN: Of those who know about their infection, our estimate is about 70 percent.

MS. DIAZ: They come from the public funded system. Are there standards in which those systems are operated, meaning that they are federally funded?

For example, if a person comes through an ATS, let's say, in Boston, is that same kind of standard of service available through the ATS in LA or North Dakota? Are there general standards are operation of those facilities?

DR. HINMAN: In the broad sense, yes. But in terms of uniformity across the country, there is not. We do not talk about testing alone. We talk always about counseling and testing. And there is more counseling done than there is testing done. There are people who come to alternate test sites who go through the process and decide not to be tested.

So that we believe that there is an important educational component to this, not just the taking of a blood specimen and the performing of a laboratory test.

Since I have the floor for a second, I would also point out that we regard counseling and testing as an important part of our educational activity, our prevention activities. But we are, in fact, investing in school-based education and mass media, in targeted informational activities. We are currently supporting, for example, more than 500 community-based organizations, which are by and large bringing educational messages to population groups which disproportionately contain individuals at risk.

MS. DIAZ: Do you also fund the HIV testing and counseling that is done in those other corollary services of public health? For example, when you mentioned family planning clinics, STD?

DR. HINMAN: Yes.

MS. DIAZ: Is there any way or documentation that you have for us today or in the future of how many people that came in through those publicly funded systems of counseling and testing have in fact changed their behavior in some way? Is that part of the evaluation?

DR. HINMAN: That is a part of evaluation, but one in which we do not have much information at the present time. I can tell you that persons who come to the counseling and testing sites, the alternate test sites, a high proportion of those who come receive their tests.

Of those who are tested, a high proportion, I can find the figure here in a minute, on the order of 80 plus percent return for the test results. Whereas -- and I can tell you that in some specifically studied situations, there have been demonstrable changes in behavior. It has been very difficult, if not impossible, to try to separate out the independent effect of counseling versus testing, or the effect of knowing sero status versus the impact of counseling and testing.

DR. ROBERTS: The problem is that unless we were to run a study in which we just gave people test results to one group and another group gave testing plus counseling, it's hard to know how much the effect is the counseling versus the pure testing, is that what you're saying?

DR. HINMAN: That's correct.

DR. ROBERTS: And then there is the ethical question about whether you could run such an experiment.

DR. MAZZUCHI: I want to echo the sentiment about the goals because, again, if the goal of testing is counseling and prevention, you don't need testing for that. The goal for individual testing ought to be to provide treatment. And as treatment, as drug therapies becomes more promising, that seems to me the only logical goal. To provide testing without providing the treatment or making the treatment available seems to be incongruous with us.

DR. ROBERTS: You're saying that of the goals we talked about, and we talked earlier, Marie raised the issue about whether we needed testing for prevention, you're pushing Alan even further. He says we do prevention via both groups. You're saying using testing as a priority setting device for prevention isn't necessary; and, therefore, to test without in any context other than treatment is inappropriate.

DR. MAZZUCHI: I wouldn't say in any other context, but it certainly doesn't seem to make much sense to do testing without treatment. I think that has to be the primary goal.

DR. O'NEILL: I think it's worth taking another minute to get a little more clarity about this issue of populations. There is, in fact, when you think about the United States, there is a population of a finite number of people who have risk behaviors that would put them at risk for HIV infection. Part of the purposes of being able to take or taking a sexual history is to identify whether this individual may in fact be a member of that group with a risk behavior.

The point I'm making is that the purpose of a sexual history is not just to identify that person but to also educate that person in terms of what they may be doing or not doing to protect themselves. So there is a prevention component as well as an identifying component that has, that occurs when a sexual history is taken.

I am saying this particularly because I don't want the point to be missed of the importance of the professional education or education of providers around these issues.

DR. ROBERTS: But there is still the difference between, which was mentioned earlier, there is the difference between saying it's important to test people who are at high risk, and it is important to test high risk populations. I mean, there is a clinical therapeutic individual diagnostic aspect to high risk, and there is a screening aspect to high risk.

DR. O'NEILL: You're talking about the difference between the clinical and screening settings. When you're talking clinical, you're saying is that person sitting across the table from me a member of that group that has high risk behavior. To the degree that the provider can determine that, A, that person will be identified as a member of that group, and, B, that person may become educated as to why they are a member of that group.

DR. ROBERTS: I don't hear any disagreement around the room about the desirability of that. And rather than keep going over that, I would like to go back to the other context, which is a little bit this question about to what extent should outreach activities and testing for both treatment and prevention be directed. I think Alan put it delicately when he talked about the community-based organizations, organizations whose constituencies contain a large percentage of individuals who might be at high risk, if I remember exactly how he put it.

I wonder if I could push you further about how you view that.

Should we be setting priorities in outreach priorities, urging people to get tested through the mass media? Are you guys about to do that? Are you urging certain kinds of people to get tested? What do you think about that?

I heard this morning when you described the five or six themes of the campaign that that was conceivably one of the things. I'm sorry, that was Alan. Harvey, and then we'll come back down.

DR. MAKADON: I guess I'm wondering whoever was using the term testing as the initial focus of the discussion is pushing everybody's buttons. And keeping the discussion from getting on to what I think is the real issue, which is how do you enable communities who might benefit from early intervention to find out about it and seek and get the kinds of services they need in order to maintain their health and prevent the development of AIDS and also to find out that they might be HIV negative and then kind of trigger a higher level of prevention.

But the testing issue kind of breaks out that issue which everybody gets so wild about that we can't even get into talking about what we would do in disenfranchised communities to enable people to find out about the prospects of treatment. I also suspect in empowering communities to do some of their own advocacy would be better than developing our own model of care which brings us to how are you going to finance it as opposed to how do you expect communities to develop a level of care and try to seek and demand it?

DR. ROBERTS: You just confused me. Are you saying that if you want communities to be empowered, what kind of a conversation can those of us who are not part of that community have?

DR. MAKADON: I guess what I'm saying is I think we should focus not so much on who should be tested or where, but do we want to let people know about early intervention, and how do we do that.

And I'm wondering whether in the process of that the demand for services and the development of services could come from the communities up as opposed to a group like this sitting and saying this is the perfect model for health services delivery, a discussion which many of us have been involved in and which always comes down to problems of financing primary health care. The recommendations have been made a million times.

It seems a different approach has to be taken in order to come up -- that would be a great goal and grade end if we could achieve it. But we've just had the same conversation too many times. There needs to be another way to get to that end. I'm wondering whether the communities at risk and people might be better demanding some of that than we might be, and we should think about how to educate people about early intervention and, therefore, develop a process where people could ultimately demand better health services.

MR. SANCHEZ: May I respond to that? I hear what you're saying, and it does make sense. But the problem is that there isn't equal access to early intervention. And early intervention is expensive. Who is going to pay for it? The insurance companies are cutting people off from insurance. They are rejecting people who are HIV positive. And Medicaid is not going to pay for it.

So you're talking about gathering people in poor communities to advocate for early intervention when early intervention is not a reality for them.

DR. MAKADON: I think it would help us get beyond the testing issue to say how do you educate a population about the problems of or the possibilities of early intervention. One side effect of that might be to mobilize people around the world. I'm not saying we shouldn't.

MR. LEVI: We can't afford to wait that long.

DR. MAKADON: I'm not saying we shouldn't do these things, but this conversation will come down to financing primary health care.

MR. LEVI: I agree with you that they are focusing too much on testing because, my assumption here was we were talking about testing as it is linked to early intervention and that we could spend days on.

DR. ROBERTS: It would now be a good time to make the transition to early intervention.

MR. LEVI: And it may be easier to go backwards to some of the testing issues. I guess that requires looking at why people aren't part of the system, the care system, for one reason or another. But I certainly wouldn't want us to end up saying that the solution is to do a lot of community organizing, to create the pressure for access --

DR. MAKADON: That wasn't my point.

MR. LEVI: We are talking about, and I think one of the messages that this Commission needs to bring back to those who can make these decisions and finance some of these interventions and programs, whatever wonderful model we construct, is that we have a very narrow window for literally possibly half a million people to be provided those interventions so that they don't become sick or don't become sicker.

But I think that if we're going to -- I think we need to separate out the testing issue as a vehicle for screening, and the testing issue as it may or may not be an adjunct to counseling without prevention and really talk about testing as it relates or talk about what early prevention needs to look like and how that relates back to testing, and what are the obstacles for people getting into that care system.

DR. ROBERTS: What are the obstacles for getting into the care system?

MR. LEVI: There are several things. One is, look at why disenfranchised groups are either not in the system or create alternative systems. Why is there a Community Health Project in New York? Why is there a Whitman Walker Clinic in Washington? Why is there the Fenway Clinic in Boston? It is because people have felt that the established medical system has not been responsive to their peculiar needs or personal needs; that they haven't felt comfortable giving a sexual history to their physician. They haven't felt comfortable letting that sexual history be part of their insurance company's records down the line.

Those are obstacles that present

themselves even to, and when you look at the original people who formed those clinics, those are relatively middle class individuals.

DR. ROBERTS: What about all the other people?

MR. LEVI: Who don't have primary care physicians at all, either because they don't have insurance or Medicaid, or even if they are Medicaid eligible, the system is so terrible that it isn't worth getting into until there is a crisis. The whole notion of monitoring and prevention care just isn't available to them for various reasons.

MS. AFFOUMADO: It's much more complicated than that, Jeff. I think you have to start from the philosophical basis of what we consider health care in this country. It is twice as oriented. It is dominated by terciary care, specialty services. It is not a prevention model. We pay a lot of money for crisis intervention. We pay nothing for prevention on a community base which would save millions of dollars.

We don't value primary care in this

country. Primary care physicians get less money, have no prestige in hospitals, there are few residency programs, there are few medical schools who want to attract physicians who want to commit to the system to do community medicine. There are very few. There are 168 residencies left in this country. The National Health Service Corps was just taken apart. You have all these 330 clinics across this country. You have staff shortages. They don't have the same salary patterning with the privates and voluntaries. You have all of these problems.

We do not value health in this country; we only value illness. We are an illness-oriented society. And this is a tragedy. This is why we have the mess that we are in right now.

Let me say one other thing because I think historically you have to look at this disease. Everybody is sitting around this table and saying isn't it nice; now we have early diagnosis and treatment. Well, we had early diagnosis and treatment ten years ago, but the reason we didn't look at it is because we have this health care system that only deals with end stage illness.

We don't allow people to come into the system when they may have a little chill. They have to come into the system when they have to go to the emergency room, like Harlon was talking about, because there's nobody who will pay for their care if they have a sore throat and a fever, but it will pay for their care if they have their heart opened up with open-heart surgery.

Now, let me finish because I think before you look at models you have to understand the reality of primary care for this disease. And I think you have to understand the history of this disease in terms of this country. Now, some of it was because we had a crisis and there were people getting sick and we really needed to look at it. But all of a sudden we have AZT and now we have early diagnosis and treatment. We have been treating symptomatically since 1983. People came with thrush, we treated them for thrush.

DR. ROBERTS: Rona, please. You've got to let me set some boundaries on your enthusiasm.

MS. AFFOUMADO: My passion.

DR. ROBERTS: I agree, and I

respect your passion, but part of my job is to help a lot of people who feel passionately and and want to participate. The point that you made at the start that I really don't want to have us get lost because it seems to me it's a very important underlying issue is the extent to which the way we deal with HIV infection parallels and plays out the way the medical care system deals with everything else. And the extent to which it's difficult or easy to construct, community outreach, prevention, et cetera, with AIDS, parallels the difficulties to construct community outreach and construction with regard to anything.

So what I hear you saying to us is there are big provider system issues here that in addition to financing and social discrimination and a bunch of other things that make this a more difficult problem than it otherwise might be if the care system was differently oriented.

MS. AFFOUMADO: I have to say one other thing. We have to define what our goal is and what our model is. I'm not saying that the money is going to be there, but then we'll understand that we have access for change in funding systems. But first you have to make a definition.

DR. ROBERTS: I just want, I heard Harvey saying earlier, and I just want to flag what is conceivably your disagreement, to have everybody say, gee, if we had a really terrific universal prevention-oriented health care system, this would be a lot easier. What I hear Harvey saying is since he doesn't think we're going to get it, he wants to have a slightly different conversation.

Am I being unjust to you, Harvey?

DR. MAKADON: No, you're not being unjust. I mean, I think we have to look at whatever we can do. It would be nice to develop a "model of care". It would be nice if that was a primary care model where people could get not just prevention for AIDS but other things at the same place.

I'm just not, I don't think it's going to work. And when you're sitting and talking about the things you're talking about, last year the catastrophic health bill got voted down. What's the prospect that Congress is going to do anything new in health care delivery, here we are in Massachusetts. And you're talking about New York City's special reimbursement health care programs. We have a really different system.

I mean I kind of feel like we need to focus on how to educate people about the possibility at the same time we're working at this end of developing a model and let people demand some services that ultimately the public sector is going to need to respond to. But without that demand, coming from people living in communities, I'm not sure anything is going to happen.

MR. GOLDMAN: I don't think that anybody would disagree that if there were access to care available that testing would be a useful tool to allow people to get it. I wonder whether or not in terms of the issue of benefit, looking at it from the perspective of the benefits of a person being tested in the context of a system in which care were accessible, that's not a true reality, is there any reason not to test other than an economic one in terms of groups? Do we end up dealing with the same issues we do in a mammography? Women over 40 should have them and women under 40 shouldn't, whatever this year's criteria may be in terms of the economics of it?

Is the issue in terms of whether or not to target HIV testing in a high risk groups, target --

DR. MAKADON: It's defining a high risk group. Women over 40 are a higher risk group than women under 40.

MR. GOLDMAN: And the reason we set that is for economic reasons?

DR. MAKADON: And also because of the risk of the false positive rate.

DR. COTTON: And radiation.

MR. GOLDMAN: So it's the same constellation of considerations that would lead us to go to a conclusion saying you ought to be looking at people who engage in high risk behaviors as being targets of the testing. Is there a different constellation of consideration?

DR. CAULEY: Except, as I'm understanding your question, choosing to have or not have a mammography or being in whatever risk group as being identified does not carry with it any potentially discriminatory factors in terms of care, housing factors. The case law doesn't suggest that they are getting that protection.

So it seems to me it does have a little bit different piece to it, in addition to the financial aspect.

DR. ROBERTS: What you're hearing is that in place of the radiation risk, there is the social risk, and the social risk is pretty high. I think, is that right?

DR. CAULEY: Correct.

MR. GOLDMAN: One more question. In terms of the issue of access, what is the difference, or is there none from what I hear, in terms of questions involving, let's say, a hypertension program or screening? There are a whole bunch of hypertension programs. Are we talking about hypertension largely affecting some disadvantaged groups who have similar characteristics, particularly in terms of minority populations, and in many parts of the country we have this wonderful program to go to your local shopping center and get your blood pressure tested and then try to make an appointment at your local clinic for a hypertension program and it doesn't exist?

I'm curious as to whether we're talking about the same thing in a different context, or whether or not there are differences in that kind of milieu.

MR. ENGSTROM: I think one of the things I wanted to comment on is I don't think we're ready to use the HIV antibody test in the same way as we run blood pressure screening clinics. I think it's incredibly dangerous. The group of people that are using the tests, in terms of individuals who engaged in risky behaviors, are the people that are getting tested once every three months. They almost place more control outside of themselves in terms of their own health the more times they get tested. And they keep getting rewarded with the negative test results.

Until we have a cure, I think that the use of the antibody test could actually be destructive in terms of our prevention goals.

The bottom line is a long-term behavior change. We have to think about the use of the test from that standpoint only when we're talking about prevention. I get very, very concerned because we made a lot of mistakes in other areas of public health education when we haven't thought about those issues and really looked at what is the individual psychology going on and how do we structure the prevention, what kinds of services, what will the intent be.

DR. ROBERTS: Could I make a suggestion? We, I think, have had a really interesting hour and a half discussion. I think this would be a good point to take a break. Let's take fifteen minutes and then let's come back and pick up with the points that Harvey and Eric and other people were raising about the notion of early intervention, more generally decoupled from testing. And let's also try to focus more about where we are compared to some of these ideals, the argument that Alvin was making to us earlier about how actual testing had been done in ways that was quite different from ideal testing.

I would like us to focus more on this gap between what is desirable and what's actually out there. Let's take fifteen minutes at this point.

(Recessed at 3:35 p.m.)

(Resumed at 4:00 p.m.)

DR. ROBERTS: A couple of procedural matters before too many people drift away, as tends to be the case in all such meetings. First of all, if you were confused about where we were today because you thought we were supposed to be across the street and we weren't, we are in fact going to be across the street tomorrow. The meetings tomorrow are not in this room.

MS. BYRNES: We are in the Essex Ballroom, which is right up on the second floor there in the Westin Hotel.

DR. ROBERTS: The second thing is in terms of schedule, the schedule you all have actually indicates 4:45 to 5:15 wrap-up. The Chairman tells me that that was initially suggested as a time when the Commission members would talk primarily with each other. Rather than do that today, they propose to do that tomorrow.

So what we are going to do now, we will run for an hour, an hour and ten minutes and then we'll just end. So that we will leave around five, plus or minus, depending upon the temperature and heat of the discussion.

Now, I heard a bunch of comments during the break, which was in part, I heard several people saying, number one, they thought some people were pulling punches. I just offer this to all of you, that some, particularly those of you who think your opinions may be unpopular, are not necessarily saying what's in your heart of hearts. So those of you who feel you have unpopular opinions, you might want to take that into account. Some of your colleagues are disappointed that those of you with unpopular opinions have not been more provocative.

The second think I heard was that it is hard to develop very quickly the degree of group process commitment that allows us to push the conversation forward, but there is, I think, some feeling that it would be useful to be more specific. And I may try to be a little more directive in pushing you to be more specific for the next hour and fifteen minutes because that may be what's of most help to the working group.

Now, we said we were going to start at this point really, I wanted to start with Harvey Makadon's issue, which I took to be granting the correctness of Rona's point that a lot of groups that are at high risk for HIV infection are disconnected to the care system. And that, therefore, part of the task is how do we connect those people to the care system and/or how do we expand the care system so that there is a care system for them to be connected to.

And I wanted to push Harvey on the issue he raised. He said we ought to talk more about informing communities about the possibility of early intervention so that their pressure for the availability of early intervention services would be a lever for help dealing with the inadequacy in the availability of services.

Like what in particular did you have in mind, Harvey?

DR. MAKADON: I think that in certain communities which got organized very early on in the AIDS epidemic, there were a lot of changes and responsiveness in the public sector to people identifying problems in the health care system and insisting that certain changes be made. I think that could probably happen on a larger scale. It would clearly be great if we could sit here and make a bunch of recommendations on how to modify primary health system to respond to the needs of the people with HIV infection as another strategy. But when you look at the enormous problems in primary health services delivery, particularly in minority communities, I'm just not very hopeful that just pursuing that strategy is going to receive --

DR. ROBERTS: Therefore, what should we do?

DR. MAKADON: I don't think, I think we should look at how we inform people about early intervention.

DR. ROBERTS: Harvey, I'm going to do it to you, since we're old friends, I can do to you what I might not do --

DR. MAKADON: I'm not an expert in public education.

DR. ROBERTS: But you said, we know, let's try to move away from some euphemisms, some communities, other communities.

DR. MAKADON: I think, for example --

DR. ROBERTS: The gay community is very highly organized around this issue. If the question is how do we get other groups equivalently mobilized, what do you think the answer is? Or those of us who are not part of these communities, as Alvin said, and, Wayne, I'm going to ask you this issue in a minute, and then Marie, because it may be that you and I are the wrong people to talk about this.

DR. MAKADON: I am a physician, and I kind of think that there are a lot of physicians working in neighborhood health centers in Boston whom we have met with recently who are very interested in doing more work with people coming to the neighborhood health centers around care of people with the HIV infection. I think dealing with that, providing them the resources, would be one strategy that would begin to get to some segment of the community, recognizing that

that would be a group that already was in some way connected with the health care system.

I must also say that a lot of the medical and nursing people whom we meet with in neighborhood health centers say they are administrators who are not particularly enthralled getting overly involved with people with AIDS because of their reimbursements from the state. So that creates a dynamic tension between providers who are far more interested than I think there is a general sense of in caring for people with AIDS and the administrative people who are worried about the fiscal viability of somewhat fragile neighborhood health centers. So I think that's something to deal with.

I think there is an ongoing issue with respect to education of the providers and education of the administrators, which I think both have to happen at the same time. In terms of getting to people who aren't disenfranchised enough to come to a health center, I don't think I'm in a position to speak to that, but it's something we need to begin to do.

DR. ROBERTS: Marie, what's your sense about how we take your advice about the alternative ways of connecting with community institutions as a source of mobilizing community concern?

MS. ST. CYR: I think there is a need for closer collaboration with the medical agencies in the community program, whether we call them community service providers or community-based organizations. The collaboration at this point is not there. We talk of one plan in the communities and then another plan.

One of the ways we can really clearly see that that information that is coming out in terms of therapies, it's not processed through the community. There is an assumption that as we talk and as we make announcements and as we use the media, that there is a logical deduction that occurs, that people screen out the information and pick out what is available and what is applicable to them. That is not really occurring. And I think that an active collaboration to bridge the gap between these two factors is extremely important.

I think clearly that it's happening in some levels, but if we're talking about prevention using existing community projects or existing community institutions, we have to activate that.

I think --

DR. ROBERTS: Can I interrupt you? What is your sense about what the barrier is to collaboration between the medical providers and the community-based organizations? Why isn't that collaboration occurring?

MS. ST. CYR: I think there is an issue of credibility and an issue of trust. In many instances there is not the sense that the people are doing the community work are credible or they are as professional. And I think there are issues of whether they trust one another.

I think the collaboration has to move where we trust these people to access the community residents and to access them in ways that the information is given, that the menace or the threat is removed in terms of HIV and its implication. And we are not there yet. HIV information is a threatening information.

I'm really upset in a way when I hear that we're talking about HIV and hypertension, and HIV and mammography. That upsets me.

DR. ROBERTS: Why is that?

MS. ST. CYR: It upsets me because when I deal with a family in which three siblings out of eight are HIV positive, after working through this family as a family, as a family group, and looking at what factors impact on these families' lives, and understanding also that hypertension when it's looked at, it's not a killer disease. Hypertension, the impact of being hypertensive and the impact of HIV positive is quite distant. So I get very flustered, I guess, when I hear that.

But just to go back to the collaborative efforts, a family, for example, just to take the same ideal situation, is one in which we have to infuse information acknowledging, for example, that a woman is primarily an educator in the family, and acknowledging that giving this person information that is clearly specific, not only to herself but to other persons whose life she impacts, is of importance. And I will take the example of these people where there are three members of the family who are positive, and believe me, this is not the only example in New York City, it starts when one woman walks in a community-based organization like ours and starts talking about her problems and concerns, and then we try to identify what family relationship exists for this woman who is currently asymptomatic. Then you move from there to work with the other families because she has a certain impact in her family setting.

Moving from there we work to provide a counselor to go to that home and sit with the whole family, who lives pretty much in a joint site. Or they invite other cousins or other members, and as we talk among them, three of them decide to get tested. Among them, two of them are positive. And so the work continues with that family.

I'm looking at that family as a unit of that whole community that is not only poor, on the immediate family, but others with whom they are concerned. There are teenagers in the community that are faced with crack every day in the street, in schoolyards where crack is being sold. Those are risk factors that we need to consider.

When we talk about HIV transmission, we talk about sexual transmission and we talk about IV drug use transmission, people don't necessarily make the logical deduction that if I go out and get drunk and I end up with someone overnight somewhere and get up Sunday morning and I don't know exactly where I am, I may have in fact exposed myself to someone who is HIV positive. This deduction really has to happen in forums where people feel comfortable to talk. And that is what is happening to an extent.

CHAIRMAN ALLEN: In what places can that take place? In what institutions? Where are the points that these, the families can be accessed in their community?

MS. ST. CYR: We work with the churches. We work with people that are identified in leadership positions in the communities, to start to bring, for example, a staff to that 15 or 20 or 50 people that are carriers, and then we provide them access to us anonymously as well as confidentially.

CHAIRMAN ALLEN: What is the response of the institutions that you attempt to access?

MS. ST. CYR: Currently it is good. If we look back at history, the response was not good. But the response has increased tremendously.

DR. ROBERTS: Wayne, I said I was going to ask you to comment about this. You've been very quiet so far today. Do you have some thoughts you would like to share with us on this problem about accessing communities that have not been connected?

MR. WRIGHT: Well, yes. I guess I have a lot of things I want to say. I heard earlier that the issue of connectedness, to the fact that people need to be connected to systems. But I think that, as one who is representing communities of color and often times people who are poor and disenfranchised, I think that if you are assuming that in being connected to those systems in our communities, that those are whole systems, that they are systems that are well and strong and viable, they are not.

I will tell you that this whole issue of AIDS and the discussion here, I think it's very important. But the people who walk into my doors off of the street are not interested in these issues, as to whether they can be tested or where they are going to be tested and who is going to be tested. The people I am working with are people who will say it is not just an issue of being accessed to services, but when I get there -- I mean, there are folks who will tell me that I will not go to the organization that you are trying to link me up to because even though I may get the service, I don't feel welcome.

And so it's not just an issue of safe environments, but it's how do you set up an environment that makes people feel welcome.

I, often times, provide technical assistance to organizations, in terms of outreach and access. And I can say to them I know how to get additional people from my communities at your meetings and in your organizations but I can't tell you how to keep them there. So if the Commission is at all concerned about one of those issues that nobody is really talking about that perhaps someone should be --

(Discussion continued off the record while court reporter's tape was changed).

MR. WRIGHT: They said the same thing about teenage parenting, same things about substance abuse. Now, suddenly, the buzz word is AIDS, and everybody in my community is suddenly supposed to be aflutter, and it's not happening. People say to me, I don't give a damn about AIDS; I don't give a damn about infecting anyone, and I don't want to change my behavior because the systems that you're now talking about putting into place have never existed for me. And if you think that suddenly I'm supposed to believe and trust that they are going to fall into place just because now the buzz issue is AIDS, forget it.

DR. ROBERTS: I asked people to be a little franker. Bob?

MR. WHITE: I would like to echo the same sentiments that Wayne had in that we in Philadadelphia go to them. We don't ask them to come to us because we know they will not use the facilities that are provided by the city or the state; that we have to go and win their trust. We go to the shooting galleries, we go to crack houses, we go to the housing projects. We have workshops for gay and bisexual men, lesbian women. We go where they are to let them know that we care. We are investing in our community, so we don't mind doing that.

I hear you say that you can't get them to hear you. I've heard that twice today. I suspect that each one of you that has said that knows someone who can't, but you won't ask them. You will not use them, for whatever reason, I choose not to suggest why you don't. But they can do it, if you will allow them to. If you are really concerned about the problem, you ask us what can you do. We tell you what we've done, how it has worked, and you suggested this on an isolated incident, a unique experience, as opposed to trying to utilize it and to see if it will work.

We have done everything that you're talking about from counseling and testing, intermediate care, or the HIV positive, asymptomatic, case management for the PWA, support groups. And if they tell us that they can't come on the subway, we will find a facility close to them, in the housing project where they can have their support group. We do not mind doing that.

You talk as if they must come to the system that you have designed as you have designed it. They are the ones with the problem. They are the ones who need the help.

So if you're asking someone who is crippled to walk to the hospital, what purpose --

DR. ROBERTS: So I hear some agreement among our last three contributors. To summarize Bob, you cannot ask people to use the system as it is. I mean, I think part of this is an answer, the beginning of an answer to the question Scott raised. Part of the answer we hear is culturally responsive institutions, institutions that express certain kinds of community control, institutions that make people feel welcome.

I mean, that's part of what I'm hearing;

that there is a really -- and this goes back, indeed, to something Alvin said to us when we started out, about how do we make people feel in what is, after all, a very difficult encounter, because it deals with sexual identity and drug use, that they can trust.

Marie, did you want to say something?

MS. ST. CYR: I want to support what Bob is saying by stating that the mentality of people walking into a clinic and walking into a setting of care, particularly in communities where there is lack of that and poor quality of that service, is to receive treatment and leave. The mentality is not associated with support and prevention and taking care of yourselves. I don't find that to be the mentality.

So we are trying to infuse a lot of focused education and prevention in the setting when peoples' mind doesn't seem to be there. And I think it's counterproductive.

MS. AFFOUMADO: Don't you think it all has to do with the fact there has been such a lack of sensitive quality, not judgmental health care, in so many communities that people don't have a history of knowing what real health care is? And so part of what we have to do is teach people how to be consumers of health care.

It goes back to maybe what Harvey is talking about in terms of getting communities to sort of say, well, this is here, and this is what I want at the same time because we don't, the reality is that the models of care for many years have been the emergency room for many of these operations in many of these communities.

MS. ST. CYR: I would agree to say that the statement I made, I did not preface it with the justification of why it occurs.

MR. DALTON: It seems to me that you're asking people to take on the task of performing the system that wasn't of their creation.

MS. AFFOUMADO: I don't think it's taking on the system so much as teaching people about themselves and how -- I don't mean themselves so much. Clearly what I'm talking about, I come out of the Sixties model of health care where we went into communities, we started trying to educate people in terms of how to fight for welfare rights and health care rights and all of those things. We weren't always successful. Many of us shouldn't have been in the communities we went into.

But I think one of the things that's happened in AIDS is this whole idea of empowerment back on the table. You can't empower people if you don't know what you're empowering them for.

MR. DALTON: Your statement about understanding themselves. Wayne and Bob are sitting here because they made the calculation that there wasn't going to be much gained by saying what was in their hearts. In the course, but to say that those people then need to somehow, and this is a problem, I love the idea of organization and empowerment, though I have problem -- but in any event, there is an assumption there that people have the time.

MS. AFFOUMADO: I have to respond to you because we are now in New York City through community services, we have put together a coalition of three communities, black, Hispanic, other types of communities in the city. There is a group in Manhattan which has been fighting Colonial Presbyterian Hospital. They are people from the community who have decided to take it upon themselves to learn what they can do to change the health care for their neighborhoods. They go to public meetings.

I think it's unfair to say that just because there are all these other issues, and I don't disagree with you, I think drugs is horrible, and all of these things, that we can't get people motivated in some ways if we make it comfortable for them to do it.

MR. DALTON: What about people who have concluded there is nothing?

MS. AFFOUMADO: They see there are successes that have been made that are small. You always start small.

DR. ROBERTS: Harlon, can I put it back to you? Are you suggesting, because I want to highlight, there is this very complicated issue of who is we and who is they and who is educating whom, and who is empowering whom. It's a very complicated issue. What is your positive response to Harvey's question, or is this essentially a matter, to be blunt, that those of us who are not people of color really have to stay out of this and wait?

What is the contribution of people outside the community to this issue? Is it to provide money and get out of your way?

MR. DALTON: That is one answer. And if we're talking about New York City where the AIDS patient gets $66,000, that's not very much money. I think that is a respectable strategy. But what concerns me even more is the sense, and again this is picking on you, that somehow you need to go in and teach people what their interests are and what they can do to alter the system as if people haven't given a lot of thought to that.

That is, it seems to me that is probably not an incorrect conclusion for you to reach that they cannot in their lifetimes do very much about the problems that the people in this room have not been successful at in their lifetimes.

I guess what I'm saying is that there is some insult in the suggestion somewhat that if they were more sophisticated or if they had more by the people that could be provided for them by the people in this room that they would be able to move a system. So I don't know that I have a positive answer to Harvey in the sense that you're asking me for, in part. In fact, I'm not of the strong position that it's only the black community, meaning blacks. But I do think that the notion that people come in to them is an important one.

MR. WHITE: One of the things that I wanted to respond to your comment about bringing the money, that's not what I meant to suggest. What I was saying -- because if you think about it, most of the blacks in this room are educated at white institutions. So we learn the same thing. We just are better able to translate and give it back to them. We are only trying to say what you're saying. But, see, if I walk through the community, the way I walk, the way I talk, they will hear me. They don't have to get past a lot of stuff because I intentionally, I guess, kept a lot of what is mine. So they will hear that.

You come, you have to do a lot of things, which is wasting more money, it's wasting time, which we don't have any of. So why don't we work together, if you ask me, try to do some of what I suggest, if you want to work with me, work with me and not have me working, not work against me. Work with me to solve the problem. Let us bring everybody who is willing to come or who wants to come or who can come to the level that they can make the decision as to whether they want to be tested, have the facility there for them so that they can make their own decision. They will make it. They have made it, and they are making it.

DR. ROBERTS: And what, in terms of what Scott said he wanted to push us on this afternoon, you say have the facility there. From your point of view, what does an appropriate facility look like?

MR. WHITE: From my point of view? Okay. I'll use what we have as an example, roughly. We are open from 6:00 a.m., available from 6:00 a.m. to 8:00 p.m. for anyone who wants to come in to be counseled, to call for information, and/or test. We do pre-counseling individually, even when we go to the shelters.

Before we will agree to go into a shelter, they have to provide a room where individual counseling can be done. Then the provider does what she does.

Then we do whatever is necessary of the counseling because sometimes we have to counsel in between while they're waiting for their results, which is only three to five days, but we provide that. Then we do post-counseling. If they are positive and asymptomatic, they can see that same counselor up to three other times before he's transferred to a counselor who will stay with them until either he decides he doesn't want to be involved anymore or he becomes symptomatic.

When he becomes symptomatic, he moves to a senior case manager who then handles all of the matters that senior case managers deal with regarding people who need their services.

We have support groups. We have an adolescent support group, female support group, gay/bisexual support group, and we have a heterogeneous group for anyone who wants to meet and relate the issues.

We, of course, also do medical referrals, housing; case managers and counselors do that. And it was not designed that way. It was not funded to do all of those services, but because the staff cares, we extend ourselves. We do it with the same amount of money that was given for a 40-hour test site. We extend ourselves because it's our community. We have no problems with that. Almost all of us took a cut in pay to come to work for the project, but we wanted to do that. That is for us. There's nothing wrong with that.

MS. BYRNES: Where do you make your medical referrals to?

MR. WHITE: You want to know the hospitals? We have several things. We either make them to hospitals, we have individual physicians who work along with us. In fact, I'm in the process of pulling together a residential, a medical group residence with Harmon Hospital for psychiatric assistance.

So we draw from the whole community. We don't restrict anyone. But we design and we tell them what we need and ask them to design their knowledge, their program to assist us.

DR. ROBERTS: What I hear Bob saying is three things that I want to flag for us because it moves in the direction of being specific. And I've also heard it from other people.

First of all, cultural sensitivity and, perhaps, cultural commonality between the providers and the client group. I think it's very interesting because in some ways I think we're seeing in the minority community the playing out of some dynamics we saw in the gay community early on. The gay community wanted to be able to deal with people who were culturally sensitive and responsive to them. And the minority community wants to deal with people that are culturally responsive to them.

The second thing I heard you say was continuity of the relationship between your organization and the clients; that once they got to a counselor, if they stayed with that counselor while they were asymptomatic, when they became symptomatic, they moved to case management. The similarity is continuity.

The third thing was integration of medical and social services; that is, the case manager had accepted, perhaps in a way that was not funded, a responsibility for managing a broad spectrum of responsibilities to the client.

MS. DIAZ: I have a couple of concerns. Who funds all of that?

MR. WHITE: The state, federal, city, and we do. What I'm saying is that our basic grant only covered 40 hours, but we give more. And most of the time we don't even write any comp time. We just give it because it's us and we want to.

MS. DIAZ: My second concern is I heard the word what should a facility look like. I really would like to, the word facility bothers me because I think we're really talking about what kind of structure, different program needs would take in serving a community. And more the facilitation of those structures rather than thinking of facilities, a facility as a physical structure.

And the last comment that I had was that from what I've heard the last half hour, we really are talking about specific challenges to various layers of community. When I hear Harlon say how we're really going to mobilize people to fight for getting more access, getting more services delivered in the community when these individuals may not be in a position to do so, I can really understand that coming from the communities that I've worked with for the last eight years in HIV mobilization. But I really think there is a place for that, Harlon, within the people that are looked upon as credible or community leaders.

And the structure that Marie is suggesting here of working with institutions that are there may be our only way of reaching large numbers of people, not only with testing and counseling messages, but HIV prevention. And I've stated numerous times that I really believe that through minority community organization and particularly mobilization of churches, we are going to be able to do a whole lot more in terms of bringing more people into this fight. Without using those established systems, it just becomes a mind boggling experience to think where do we have a crack at mobilizing large numbers of people around this issue.

What I've heard today really bothers me in terms of the repeated use of the word treatment and early intervention because I think we're still talking very much in a medical model. I submit to you that within the communities I've worked with, the model that probably would have a greater chance at developing the opportunities for dissemination of widespread education, prevention, options, offering people and communities options for how they should go in this testing issue, would be done much more aggressively and better through a social model.

DR. ROBERTS: Could you say what you mean by a social model?

MS. DIAZ: She described it for you. Taking in the work and establishing a good relationship with community-based organizations. Why couldn't there be a message of early intervention and prevention broad based through community organizations, or through churches, or through Head Start groups, continuing that, rather than saying we're looking at treatment, associating the testing with treatment.

After all, we've got to look at the fact that many people in minority communities are not going to either accept medical treatment, even if you said, look, this is what is available; that if in fact you get to a health facility or health care facility you may be able to have such a drug. They are not going to take advantage of that and absolutely decide to do things that are self-empowering or what that culture has determined are good ways to handle illness. Some of these may be natural remedies, better nutrition, lack of certain stressors or reducing the stressors that are facing us.

I see some of you agreeing with this. But I'm just telling you that for us to try to impose a medical model on the way that certain communities ought to act may not be in our best interests, or even an understanding of how those communities deal with a perceived threat of illness.

DR. ROBERTS: We'll come back around, but what I hear Eunice saying is that if we are going to be culturally sensitive, part of that cultural sensitivity involves the extent to which we medicalize versus non-medicalize. Harvey is not here, but I was interested that when you asked the doctor, how do you outreach, the first thing he talked about was other doctors. I hear you saying, well, there's really other ways to think about this.

MR. SANCHEZ: I'm really glad you said that, Eunice. You covered a lot of ground there for me. I think that the discussion has really come close now to what the heart and what the real problems exist in terms of health care and HIV infection. And I think Wayne also from bringing up the racism because a lot of it is the pre-existing prejudices that were, in effect, since day one.

Now, in the work that I do, what I encounter a lot is classism that comes up daily in terms of the stigma and discrimination, AIDS-related discrimination.

What I would urge --

DR. ROBERTS: Could I ask you to say a little bit more about that? You say you encounter classism daily.

MR. SANCHEZ: I'll give you a quick example. I did an advocacy whereby these two guys went into a fast food restaurant, ordered burgers and fries and a soda, sat down and started talking about AZT and Compound Q. These are two guys that are involved in Veterans Hospital and Beth Israel, so they are involved in methadone as well. So they come back two days later and they sit down, they come in and order, and nobody would serve them. Everybody is backing up off of them, would not serve them.

As they are leaving the restaurant, an employee that is cleaning the tables tells them, hey, they wouldn't serve you because they heard you talking about AIDS.

I spoke with the manager, I did a training for the employees of restaurant, and next week I'm doing a training for 90 managers of this particular chain, part of the systemic work that they are trying to do. But in my opinion, if it had been two doctors sitting down at that table talking about AZT, they would have been served, you see.

When I went back and spoke with the

manager, part of what she said, well, you know, they're on methadone, they come in here and they'll buy soda and stay a half an hour. If they went to the Waldorf, they wouldn't serve them there, either. So this is a classic classism example.

But I'm going to speak very briefly and quickly. In terms of the Commission, I would urge the Commission to, in any implementation of policies that they take into consideration all aspects, not just the medical and the -- not just the medical status or the treatment aspects, but also the social aspects of policies because there are many policies that are in place, in hospitals, in government, in industries, that are in good faith but are discriminatory. They have discriminatory traits inherent within the policy.

You raised something about facilities, and I'm just going to use the word because of lack of a better word. But in terms of a recommendation, what I would like to see in communities is a comprehensive health care facility whereby a family can be treated. The family can come in, they can be tested, and they can be treated, counseled, safer sex practices, safer IVDU, be treated for whatever opportunistic infection they have, not go to the east side for one treatment and go to the west side for the other and get the run-around around town in terms of dealing with their HIV infection.

MR. LEVI: Before you leave that, could I ask you one question of clarification? Do you think that integrated care for the family should be part of a separate HIV systems?

MR. SANCHEZ: No. That contributes to stigma. Nothing should be separate; it should all be together. And I reject the idea of housing for PWAs.

MR. LEVI: I just wanted that to be clear.

MR. SANCHEZ: I think we should try to engage the private sector. A lot of times we think in terms of government and getting more money from government. The reality is that government is limited, and the groups of people, the population that HIV infection is affecting are not favorable groups of people for those that are in power, in terms of the government. It's predominantly the gay population, the intravenous drug user.

So what I would suggest is an approach where we reach out to the public sector and get them more involved in terms of education, and the idea behind it would be that it would be cost-saving because employees are getting sick all over the place. It's costing money for the employer, their health insurance premiums and rates are going up. So it's on that idea which is a realistic thing. And the private sector, there is a lot of money that can be gathered from there, needs to be thought out more, but I'm just suggesting that.

In terms of the news media, I think that they can play a more responsible role. I know that in New York City, I'm sick of getting on the subways and looking at these ads that still talk about "the AIDS virus", and "the AIDS test". I think we really need to address that, also, because it also reinforces the misinformation that people already have, and they are already confused enough. We see more and more of this on printed ads and television.

And one last thing I'm going to say is regarding prisons because I'm an ex-offender and I've been through the criminal justice system of New York State. I've been out of the system now for ten years. I go into three correctional facilities on a monthly basis, state facilities. And when we talk about testing out here, routine testing or the idea of a massive screening, that translates into mandatory testing in prison.

And I speak routinely, I go to a female facility and two male facilities. And there are people who are being tested and not told their test results, people being tested within correctional facilities in New York State without pre- or post-test counseling. And the lack of education and understanding that they have regarding HIV infection is minimal, at best.

So that when we talk about targetting a particular group of people, let's think in terms of that group who are coming back into our communities, who are in a confined situation where education can be offered. And you look at 60,000 people who are incarcerated in New York

State, and 60 or 70 percent of them have histories of drug use.

DR. ROBERTS: Before we push on that last point, I want to go back to the point that Jeff raised. If we're talking about models of systems and so on, this question about the extent, and Harvey raised it earlier, the extent to which care for people with HIV infection ought to be integrated into the rest of the medical care system versus separated. And the reason why I want to re-raise this question with you is that there are at least some situations and circumstances in which people with HIV infection have been treated better than people with other sorts of medical conditions by the medical care or social service system.

There are examples in New York City where it's easier to get housing if you're HIV infected than if you're not.

MR. SANCHEZ: That is absolutely wrong.

MS. AFFOUMADO: He is absolutely right. What are you talking about?

MR. SANCHEZ: In New York City, in

order to get housing you have to have an HIV diagnosis.

MS. AFFOUMADO: I've got people in housing with HIV --

MR. SANCHEZ: Homeless?

MS. AFFOUMADO: Yes.

MR. SANCHEZ: You and I need to talk then.

DR. ROBERTS: All I'm trying to ask you is one of the difficult problems of, I'm not taking a position, one of the problems of an integrated system is that, going back to where Rona started us, then if you're going to improve the care for people with HIV infection, including those who have progressed to AIDS, you are going to have to improve the system in a sense for everybody; whereas, if you don't have an integrated system, you have in that sense less of a burden. And I'm just wondering what you feel about what seems to me a difficult question.

Do you still think that an integrated system is the only sensible way to go?

MR. SANCHEZ: I think it's better than what we have now.

DR. SMITH: I think there are models of care that can be used of chronic disease. I would cite the hemophilia model in which the patients which we actually considered our friends have been coming to the hospital all the time, and through the treatment for fairly complicated diseases, by treating themselves have been able to go out and provide about 90 percent of their own care. I think that such a model can be applicable to the HIV situation.

DR. ROBERTS: In what way, Peter?

DR. SMITH: Also, it's a non-medical model. There are big differences, obviously, but it can be used.

The other thing that I would like to emphasize to the Commission is the fact that there is at the present time pretty much a dichotomy between diagnosis, prevention, education and treatment. And that should not exist. There should be a pretty easy step between the diagnosis and the education to the next step, which would be treatment, even though we don't have the ideal treatment now.

I think that although I agree with Marie and with Romeo that the system needs to be more user-friendly, it's very hard to force people to be friendly. But there are things that you can do. You can tie federal dollars, you can tie the grant's amount, the fact that there is an active outreach program, any sort of a clinical trial, that some dollars are certainly contingent upon an active outreach effort. I mention that specifically because I, myself, am very sensitive to the fact that I live down in Providence, Rhode Island, which is only an hour away from here, and I cannot get my kids with AIDS on clinical trials that are approved right here. I have been working since August to get my kids enrolled in trials. They are like the cutting edge. They are like cancer therapy. They are the best around.

So you have to use secondary mechanisms, like INDs. So I think the government can put a better effort by putting organizations together that do some of these clinical trials, and some of the service projects, so they link up together, talk to each other and are more responsive.

DR. ROBERTS: Can I go back to the hemophilia example because I think it's clearer to you than it is to some of the other people in the room what you're referring to when you produced that example. You said these people come to the hospital, and then you said this is a social, not a medical model. I tend to think of hospital-based services as medical not social models.

Perhaps you could say a little bit more about what you have in mind.

DR. SMITH: Let me clarify my point. It is a hospital system only inasmuch as most patients come to the hospital once a year, perhaps two, three times, depending upon their medical problems, which often are many, particularly now with HIV infections. But a very significant part of their treatment is self-administered, and it's complicated treatment. These people have to give themselves an intravenous injection. They have to know everything about sterilization and everything. It's a fairly complicated system.

We are doing that with all levels of

patients. We are trusting them with the care that they provide for themselves. So I think in that sense it's much more of a community-based model than it is a medical model.

DR. ROBERTS: When people talk about community-based programs, they often don't mean just that the people live in the community.

DR. SMITH: Home-based.

DR. ROBERTS: Denman, I said you could speak.

DR. SCOTT: I would like to make a couple of comments. First, concerning the medical versus social model, I don't think it's an either/or situation. It is really both, and and when you use either, and the route to whether you want social support, psychosocial services, working through a variety of community-based organizations, or you're working in medical care, through a good case management system.

As I listen to the comments around the room, I get the sense that there has been no progress whatsoever in the years that we have been working on the epidemic. And it sounded very discouraging to me if I were a Commission member and hadn't been on the front lines at all. I think, in fact, there has been enormous progress made in various ways around the country. That doesn't mean there's still not a long road to travel. There has been progress, certainly in our state, on any number of issues. We are moving towards a very comprehensive set of services. The skill level in any number of different social and medical systems has been amplified many fold over the past several years. And all the people we identify as positive from asymptomatic through symptomatic, it appears, as we study this, are integrated into a set of social and medical services.

What I think you need to do as Commission members is, if you haven't already, go out and look in very great detail in various parts of the country about what's working, what's not working, what kind of testing programs are in place, and not just listen to people talk to you because you're never going to get a totally accurate portrayal through this kind of commentary, in my judgment. I have a lot of stuff I could tell you about our testing, our case management, our prison program.

You mentioned the prison program in New York. We had a prison program in Rhode Island which was launched in the prison. It is run with the Department of Health and Brown University School of Medicine. I think it's one of the first programs in the nation which actually is integrated into a residency and fellowship training program. Everybody in that prison is counseled. There is a mandatory testing program by law, but that program couldn't go forward until the counseling was in place, the medical care was in place, and the aftercare referral systems were in place to take care of those who were positive.

That is in place and it's working. It's not perfect. No social or medical system is perfect, but, by God, we've made a lot of progress.

CHAIRMAN ALLEN: I might say something about the Commission. We are traveling around the country, been to LA. We are going to be going to New York City and New Jersey and dealing with the homeless issue and the children's issues.

MR. DALTON: The rural south.

CHAIRMAN ALLEN: We are going to Alabama and Georgia and dealing with the rural issues there, so that is part of our task.

DR. SCOTT: Get some of the suburban issues and the middle size issues.

CHAIRMAN ALLEN: When you talk about how far we have progressed, that is true. But it seems to me that are we ready for the expansion, the increase that we're going to be dealing with? And it's like trying to add on another room to the house in the midst of an earthquake. Everything is shaking.

Here we are with early intervention, but is it there? Is this an illustration? Is it something that works well with white, middle-class people? I was going to ask about the hemophilia regional centers.

Is that a model that is applicable across the board? I don't know if that can really be easily accessible to communities that are not already geared for that kind of mentality or expertise. And everything is shaking here. It is a rather precarious situation. There needs to be a lot of thought going in to the direction as we move.

I agree, we have come a long way, but we have a long way to go. So that is my feeling and apprehension about it all.

DR. ROBERTS: Kate, and then we'll come to you.

DR. CAULEY: I just wanted to make a quick observation. I happened to glance at the agenda and noticed that the topic is the role of testing and early intervention. It certainly seems to me in the course of the last two hours if one were to ask at this point what is the role of testing and early intervention, the answer would be, at least amongst the populations where the infection seems to be growing most rapidly, to simply be available when we're ready to use it. I think that's an important point to make.

MS. ST. CYR: I just want to ask Denman a question. I want you to tell us your state and how many people that are HIV positive that you have to deal with.

Secondly, also, share with us what factors have come across the table to damper your optimism, to reduce it. That was your statement in the beginning. If you were to hear what's spoken around the table --

DR. SCOTT: It just seems that people feel like, I have a sense that we're starting right at the beginning with this massive problem and nobody has learned very much or done anything. I think if you look at the number, I just have a sense of, gee, we haven't gotten anywhere. We have gotten a long way. It's still a huge problem. But just think of the thousands of people who are skilled, capable and able to deal with this now that weren't there just five years ago. There is a small batallion of people.

DR. ROBERTS: Could you say something in response to Marie's other question? How many cases Rhode Island is dealing with and a little bit about their ethnic and class composition?

DR. SCOTT: Sure. We have had symptomatic case reportable disease, 310 reported since 1983, which puts us in the top third of states. We have begun a testing and counseling program which requires physicians to offer the test in a number of clinical settings. Nobody has to take it, but they must be counseled and offered the test. That's just getting going.

In addition to that, we have run and will continue to run anonymous test sites for those who really feel that anonymity is crucial for their ability to be tested.

DR. ROBERTS: Just if I can push you on the numbers because out of the 310, how many of them are cases currently under treatment roughly?

DR. SCOTT: I wanted to say that half of them or two-thirds of them have died.

DR. ROBERTS: So a hundred is the number of cases?

DR. SCOTT: No, no. The testing program has identified in the last two years 800 HIV positive individuals. Our three major clinical centers for taking care of AIDS have enrolled 650 individuals. And the private practicing community has a number enrolled that we are currently ascertaining. But we think, by virtue of the case management, nobody is identified as positive who is not referred both for social/psychological support, or medical care as the way we go through our testing program now.

So we think everybody, and this is approaching probably a thousand people, is being taken care of reasonably well.

MR. LEVI: As someone who was at the LA hearing of the Commission, I would like to turn the tables on your request of the Commission. You suggested that the Commission, that people were hearing too many negative things. I think if you had been in LA, and maybe you ought to visit some of the sites that the Commission visited in LA and listen to some of the witnesses or look at the record of the hearing in LA, you couldn't help but be moved at how far we are really from the beginning. And in a more middle class community, in a more, shall we say, homogeneous, ethnically and racially community, and I would be happy to say in the white gay community, white middle class gay community, yes, you can point to a lot of wonderful things that have happened. But for so many people, the nation's response, the system's response to this epidemic is truly just beginning, even, I think as we saw in LA, even in some of the communities and some of the states that when they leave their home territory can give wonderful speeches about all the wonderful programs they are supporting and services they are supporting, but in reality for the people who are facing this epidemic it's not there.

But, what I would like to do now that I've seized the floor, is return to the issue of whether or not there ought to be separate facilities because I think that is a really major issue. I only have one or two thoughts about it, we're almost done for today, but I really hope that we will spend a significant amount of time on this because that, at least, in a lot of the minds of medical and public health people, is an issue for debate.

The two thoughts I would put out is I am concerned it will create the stigmatization of a separate facility. AIDS is very different from other diseases. It becomes an excuse for those in the health care profession who don't want to deal with the issue to dump it somewhere else.

I am also concerned about the level of monitoring that can occur in every community. It's one thing if you have a separate facility in San Francisco and quite another if you have one in other communities where there isn't going to be the level of monitoring in that separate facility, and at what point does that separate facility become a dumping ground or a warehouse for people. And, I guess, that, just because we're integrating HIV care into the overall system, doesn't mean we have to reform the overall, the entire system and everything about the system in order to make it accessible for people with HIV.

Indeed, we can say we're going to take the HIV part of the system and reform it to create some models. This is what we should be doing for every disease, we are in effect pushing the system toward reform without having to take on the entire system.

DR. ROBERTS: I take your point. Certainly the existing system is extremely uneven in its coverage by disease, so we obviously, your point is certainly well taken.

DR. NOVICK: Bob, when he spoke, called to my attention something that we haven't said clearly. We have a second crossroads now. We don't just have the opportunity for early intervention. We have another crossroads.

In the early part of the epidemic, we depended on people like Bob with a calling, people like me, too, and probably most of you at the table, who had a calling and wanted to work 120 hours a week and didn't ask questions. And that has been a very successful model. But we are now trying to match those people with the medical model where there is also a calling, but it's a calling of a different sort. But that is what we are facing because we probably cannot arouse tens of thousands of people with callings.

Harvey would like us to arouse the political voice in the underrepresented or disenfranchised communities. I would like to do that, too, and I work on that all the time. We do it to some extent. But, again, you're asking for the creation of people with calling, and we all wait for that and we value it and we honor them. But we can't really call them up. They have to call themselves.

So what we are asking today is how we link those wonderful people to the health care professions, I think, because at this moment that's what we need. I mean, it's the same for people like Peter that have been called to the care of those with hemophilia. That's what we are around the table. Now we have to enlist the other four hundred thousand.

CHAIRMAN ALLEN: Along the same lines, we haven't really discussed the issue of burnout and the issue of those that have that calling are getting tired. And where is the next phase? And as we are now moving into this early intervention mentality in the system, there is going to be an onslaught to access the system. And the professional care, it's not there. People cannot continue to work 120 hours. And where is that going to be picked up?

I'm very frightened by the setup that we have in our society right now. And it is extremely chaotic, as far as I'm concerned. That is something that we need to think about, is the burnout, which we will probably get into tomorrow with the psychosocial. We'll have to.

DR. MAKADON: I think we can only go so far with the discussion of kind of models of care. I guess some of my comments are not unrelated to what I said before. I have been a proponent of integrated care, but I think Deborah Cotton in her testimony before the National AIDS Commission back in November pointed out there are certain aspects of care that are getting so technical that it will be hard for that all to happen in mainstream delivery of care health systems. I have to say that our own experiences validate that.

My concern now is we probably shouldn't spend too much time considering which model is best but begin to think which services need to be provided and how we assure quality, regardless of what the system is. If we spend too much time designing the appropriate system, it's never going to work in all places. It may be that what's best in San Francisco isn't going to work in Omaha. But, in fact, all people in all places should get access to a certain level of care.

And in terms of early intervention, it's relatively easy to say people who have had HIV testing done should have at least had a T-cell count done. And if it is such, are they on AZT, and look at things like that and get a sense of how we are going to monitor the quality of care people get and get some semblance of a system out of that, or see if the system is working.

DR. ROBERTS: Harvey, I want to push you on this business of quality of care versus what Marie said earlier. At least as I heard the conversation, one of the devices that the medical community uses in its mutual lack of trust with a community-based organizations that Marie was talking about is this business of quality of care.

I wonder whether you think I'm being unfair in saying that. But we've often heard about quality issues as an excuse for maintaining the monopoly of control in certain systems and institutions by physicians.

DR. MAKADON: I don't know exactly what you mean. It seems if you define quality broadly enough to include a sense of what the consumers are receiving from the system and actually quantifying that in some way, that is a way of judging how the system is performing that that might get around that. I don't know if that meets your concerns or not.

DR. ROBERTS: But all -- your answer is that it's not a problem if we define quality broadly. On the other hand, it's conceivably a problem if we define quality narrowly.

DR. MAKADON: I guess my concern is that if we're talking about a system in the abstract, we can define a very nice system and be pouring lots of money into it, but it may not be delivering the kinds of services that we hope it delivers.

DR. HINMAN: Getting back to the idea of early intervention, it seems to me there's probably agreement that early identification of infection is desirable if there are available, acceptable means of providing intervention. The question that comes, several questions arise. One of them is what do you mean by early intervention? There is the medical model intervention, if you will: Testing T-cells.

And I would point out that another important early intervention is tuberculin testing and the provision of preventive therapy for tuberculosis, and the provision of methadone programs for IV drug users. These are early intervention in HIV infection which are not mentioned so much now as our Pentamadine and AZT. And these are not yet fully implemented. But there are a series of more or less medical types of intervention that can be defined and can be stated to be an important component of what one does.

There are an equally important series of social psychological interventions, which may not be as yet as well defined, and about which we do not have good models for provision. I mean, we do have, with all of its faults, a medical care model in the United States which has provided with a lot of unevenness a series of types of services, often fragmented, often at the wrong time or by the wrong kind of people, but something is there.

For many of the social and psychological interventions, I don't believe the mechanisms are still in existence.

DR. ROBERTS: Could you say more about what you think those social and psychological interventions are?

DR. HINMAN: Some of the things that have been talked about are support groups. How do you deal with the anxiety of being infected, not knowing when you're going to get symptomatic, not knowing what is going to happen to your job, with your insurance, these kinds of things. These kinds of support groups exist in some areas for some conditions, but there is not, I think, a widely developed approach providing this kind of support.

DR. ROBERTS: Let me push you another step because in another life I moderated a discussion of a somewhat similar sort about early intervention for pregnant women in the minority community, and the question of what were social interventions. And people began when they started to think about it, about everything from court orders to prevent wife abuse to income supplements so that people had enough to eat. And I'm struck by the modesty of your response to my question, to be a little unfair.

I mean, do we -- is early intervention support groups to deal with peoples' anxiety about not having enough financing, or is it money so that they have enough financing? To take your point, once you start down this road, you open a pretty big door.

DR. HINMAN: I'm aware of the fact that there is a very large door which I don't think, as we've been talking about, we are in a position to effect the overall change in American society that is going to solve all of the problems. I guess, first of all, I'm in the public health business, so I tend to think about kinds of services that might be available or how one might try to make them. And the example support groups was the first thing that came to mind.

DR. ROBERTS: I'm being unfair to you. I understand.

MR. DALTON: I was sort of hoping

Alvin could do this, but maybe I'll do it myself. I also thought maybe I would wait until tomorrow because it hits on the psychosocial, and that has to do with the sort of role of physicians in dealing with this epidemic. The conversation about medical model, medical people and nurses, I thought that was an interesting separation of professions.

Our friend in uniform was talking before, I leaned over and said he was a doctor because he was speaking fondly about his program, I heard the word nurse practitioner several times in the course of his remarks, all of which -- I'm remembering Jeff's remarks about early on in our conversation today about whether physicians were really very good at figuring out who is at high risk because of a congenital or at least cultural inability or difficulty in getting things like sexual history.

My question to him was whether he thought that doctors were in fact educable to the point that they could provide counseling, they could in fact take sexual histories, they could in fact make a bridge between the medical model and the social model, that they could be concerned about family systems and what's the role of women as a health educator in the family, capable of seeing the information needed to give beyond sort of science, at the risk of having needles stuck in their arms.

I guess I want to put on the table that maybe part of the problem is that we have too constricted a view of who the medical people are -- .

DR. ROBERTS: You swallowed the end of the sentence. You said we had too constricted a view --

MR. DALTON: Of who medical personnel are or ought to be. Then, again, the quality of care discussions just brought up for me all sorts of debates about credentialing. I've sat on the task force, Health Department Task Force in Connecticut in which the question came up about who should be doing counseling. Every doctor in the room said only doctors because, and the rest of it didn't make a lot of sense. It seemed we were talking about professional rivalries. I mean this to be sort of opening up some conversation for tomorrow --

DR. ROBERTS: We are not going to settle the role of physicians in the next two and a half minutes.

MR. DALTON: I think --

DR. ROBERTS: You get a chance to respond.

DR. COTTON: I won't be here tomorrow. Well, I mean, I just find it interesting that in a group where we've been, I think, exceedingly careful to be sensitive to not speaking about communities that we're not part of, Harlon finds it very easy to speak about physicians, which he's been doing. I think we've talked a lot today about the medical model and social model. We've talked a lot about whether or not we really need to adopt a medical model.

I think that I first want to say what my own obvious biases are. I've already testified to the Commission as somebody who believes we do need regional AIDS centers. I realize that's quite a minority view. I feel it very strongly, however. I think that the reason for that is that this is an extremely complicated disease.

And no one is saying, I don't believe, that only physicians should be involved in caring for HIV infected people. I never counsel people about HIV testing. I'm not particularly expert at it. I refer them to the very good counselors that are available to me to do just that.

Mark Smith from Hopkins spoke eloquently about our need to train nurse practitioners. I don't think any of us who are totally overwhelmed who ever say that we think that only physicians should be doing counseling or providing 90 percent of the care for asymptomatic people. What I do think is that this is a very complicated disease. I think the therapies are becoming more and more complicated. I hope that they become even more complicated because if they do, it will mean that we are really going to be able to eliminate this virus. We have several promising therapies that are about to go into trial. None of them, unfortunately, are pills. None of them are drugs that we expect to have no toxicity.

I think it is likely that we are going to need not only physicians but infectious disease physicians, or, and I would favor this, AIDS physicians to care for these people. I think we have to be part of this. To say that we don't need to have physicians as part of care, as part of early intervention, is simply not true. We need it. We absolutely need it.

MR. DALTON: I didn't say there was no role for physicians.

DR. ROBERTS: I am going to give the three people whose hands are up a chance, and then we are going to have to close.

DR. CAULEY: I wanted to briefly pick up on the conversation that Alan and our esteemed facilitator were having to just frame something for a moment. It might be useful, it might not be.

When you talk about early intervention, if you talk about social early intervention, then we've got education, empowerment, all the things that we've had on the table, for which it might be said that the choice or decision to be tested or not be tested is the end result of social early intervention; whereas, when we're talking about medical early intervention, the test is the first step because we can't provide medical early intervention until we know a person's T count, et cetera. I'm not sure, but for me that helps to make a distinction.

DR. MAKADON: Can a doctor talk to a patient about social intervention --

DR. CAULEY: I'm not getting into that.

DR. ROBERTS: All right.

MS. AFFOUMADO: HIV is a very complicated disease. It's complicated not only on a medical level; it's complicated on the psychosocial level. What we're really talking about is groups of people who are providing many levels of services using many different kinds of providers. We are talking about lay people, talking about professionals, talking about all kinds of things. What we're really talking about is multidisciplinary models.

One of the misnomers in discussing HIV is this whole thing of case management. It's not case management; it's team management. It's management of groups of people, whether they are in one location or they are in the community or they are in other places. These are very complicated problems that we're dealing with.

We also have to remember that we are talking about a disease, a disease that has certainly prompted many, many other types of problems. There is no doubt about it. I think Deborah is absolutely right. I work in a clinic. I see the kind of medical monitoring that must take place in order not to kill these patients. Look at what we're doing to them. We are giving them highly toxic drugs that we don't know a whole lot about. We are developing all kinds of protocols that we have very little experience with. We are learning by doing a lot.

Now, again, I'm not putting values or judgments on any of this, but I think we have to look at the reality of how we're managing these patients and what it really means. We keep saying AZT, early intervention. I know in our clinic with the 2,000 patients we have in our clinic, AZT lasts about eighteen months to two years. Is that really early intervention, or is that holding people in holding patterns?

Pentamadine, we just did another study on our patients in our clinic, it breaks down at around 24 months, also. Now, whether that means forever, I don't know. But what I'm saying is that early intervention is really holding patterns. We don't really know what these medications are doing to people at the time. We really need to be very careful about talking about research trials, monitoring our patients and not having backup services and all kinds of things. I think we have to be very careful when we look at this because this is very dangerous ground that we are sitting in medically.

We talk quality. We don't know what quality is for this disease. We really don't in some levels. So we have to be very careful to not be simplistic of what we're taking care of here. It's very complicated and there are lots of issues here that really have to be looked at.

DR. ROBERTS: Don?

MR. GOLDMAN: I would like to make two observations. The first observation is that it has always seemed to me rather presumptuous to assume that within a given community, and specifically in the black community or in the gay community, or in the Latino community, that issues of AIDS, HIV infection, are in fact the important issues within that community. They may be important to some of us who are working within that arena. But many communities are afflicted with many different kinds of pain and suffering of many different kinds. It's not true that AIDS is not the most important thing in the world. It may well be to a certain family the fact that they are affected by HIV may be the most important thing to them. But in the realm of things to many people in many communities, it's merely one somewhere down the list of problem number 7 on a list of 6 which were more important to it. And we really can't make that presumption.

In order to empower a community to advocate the kinds of separate facilities that are required for it, that community makes its own judgment as to the priority of AIDS and HIV infection in terms of the value of its own system.

We can, however, deal with the

institutions with which we deal. If we deal with medical institutions in some way, we can make sure damn well that for those members of those communities that access the institutions with which we deal that in fact they can be sensitive to those cultural kinds of differences. We may not be able to impose our wish on another community, but we can certainly make sure that our community is appropriate.

In terms of dealing with empowerment, the issue of empowerment is do we really want to go into communities and tell them what their priorities ought to be or do we want to let them develop their own priorities, and maybe those priorities will not be AIDS and HIV infection. Maybe there'll be job training.

The other point I wanted to make which is sort of entirely unrelated, I think people ended up getting to, is talk about a dichotomy between a health care model and a social model is not necessarily a useful dichotomy. The health care model, if in fact it's done right, in fact you have the appropriate multidisciplinary team approach, is in fact a social model. I think what Peter Smith was trying to say is that probably we spend 70 to 80 percent of our time dealing with social issues, dealing with how do you get people eligible for the various reimbursement programs that will enable their care, how do you get them into the community mental health system which provides it with affordable psychotherapy, how do you get them in terms of what social agencies get them some kind of housing, how do you deal with vocational rehabilitation to get them job training, how do you interact with that to make sure it's done consistent with a very, very complicated medical disease, and those, I spent 70 percent of my time dealing with bureaucracy, payment and social issues. That's what's involved.

It's true of many models of chronic diseases that deal with the whole gamut of chronic disease in a multidisciplinary team, it's really the same. The social worker, the nurse clinician are probably more important to the patient than the physician is. Not to be disrespectful to the physician, but in terms of who they interact with on a daily basis, and those are very, very important members of the team. The models are not at all diverse and they are perfectly consistent with each other.

DR. ROBERTS: On that note, Mr. Chairman?

CHAIRMAN ALLEN: I would like to thank you all for being here and thank you for your calling. A couple of observations as there has been some doctor-bashing, I want you to know I am extremely relieved being a minister, I usually end up in meetings that do a lot of minister-bashing. So it's kind of a relief for me at this point.

I would like to say that it sounds to me like what we have been talking about is that not one model is going to fit all cases. Yet, at the same time, we have really compartmentalized our approach to this illness because we've been putting out fires for about eight years. We run here, put out something here, run there, put out something there. There is always a sense of urgency. As I say, we hear the positive things around this country, but you don't go to marriage counseling to tell the counselor all the good things about your marriage.

So we have come here to talk about the things that are wrong, the things that are hurting. And you have articulated them well. It has given us a lot of food for thought on early intervention and testing; that we need to move in a rather careful manner through this process. We will continue to look at the issues and to try to make some type of recommendation to the full Commission. We are not coming out of this meeting saying this is going to be the policy of the National Commission on AIDS. We are fact finding and trying to gather this information and we'll take it all in.

So this is the beginning of a process, and it's going to be a very thorough process.

As for tomorrow, I would like to say that we are going to be meeting at the Essex Room in the Westin beginning at nine o'clock. I assume you all have these questions, the three questions that we will be dealing with tomorrow.

Thank you again for helping us.

(Hearing adjourned at 5:30 p.m.)

CERTIFICATE

COMMONWEALTH OF MASSACHUSETTS

SUFFOLK, SS.

I, LISA W. STARR, a Notary Public in and for the Commonwealth of Massachusetts, do hereby certify:

That the said proceeding was taken before me as a Notary Public at the said time and place and was taken down in stenotype writing by me;

That I am a Certified Shorthand Reporter for the Commonwealth of Massachusetts, that the said proceeding was thereafter transcribed into computer-assisted transcription, and that the foregoing transcript constitutes a full, true, and correct report of the proceedings, to the best of my skill and ability, which then and there took place.

IN WITNESS WHEREOF, I have hereunto set my hand and Notarial Seal this 21st day of February, 1990.

Lisa W Starr

LISA W. STARR
Notary Public

My Commission Expires: May 13, 1994.