DR. SerVAAS: Why don't you test in your STD clinics for HTLV-I?

DR. CAINE: Okay. We are. We just started in November. I just wasn't able to give him the type of statistics because we're so early in our testing.

DR. SerVAAS: Okay.

DR. CAINE: But our STD clinic is predominately 60 percent black, 40 percent white, of the clientele that we're seeing in our STD clinics.

CHAIRMAN WATKINS: Thank you very much, Doctor Caine and Mr. Garrett, for being with us today. I think it was very important and I will be calling Doctor Cobb and thanking him again. I'm sorry that we dragged you all the way to Washington when we were about ten feet from you last week.

DR. CAINE: Oh, that's quite all right. It was very interesting.

CHAIRMAN WATKINS: But, you're very special today. You see, we don't have many panels where we have one witness. So, anyway --

DR. CAINE: Any excuse I can get to Washington is quite all right with me.

CHAIRMAN WATKINS: Thanks very much for coming. We appreciate your testimony.

DR. CAINE: Thank you, and we'd like to thank you for the opportunity of letting us come before you. We're very appreciative. We think you're doing an outstanding job.

CHAIRMAN WATKINS: We'll stand adjourned until tomorrow morning at 9:00.

(Whereupon, at 5:28 p.m., the above-entitled matter was adjourned to reconvene tomorrow at 9:00 a.m.)

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

FINAL HEARING

The Hearing was held at the
Interstate Commerce Commission Building
Hearing Room B
1200 Constitution Avenue, N.W.
Washington, D.C.

Wednesday, May 18, 1988

COMMISSION MEMBERS PRESENT:

ADMIRAL JAMES D. WATKINS (RET.), CHAIRMAN

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

CORY SerVAAS, M.D.

THERESA L. CRENSHAW, M.D.

BENY J. PRIMM, M.D.

POLLY L. GAULT, EXECUTIVE DIRECTOR

COMMISSION MEMBERS NOT PRESENT:

COLLEEN CONWAY-WELCH, PH.D.

JOHN J. CREEDON

RICHARD DeVOS

BURTON JAMES LEE, III, M.D.

FRANK LILLY, PH.D.

PENNY PULLEN

I-N-D-E-X-

I-N-D-E-X(continued)

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

9:01 a.m.

EXECUTIVE DIRECTOR GAULT: Good morning, ladies and gentlemen, distinguished panelists this morning. This is the last day of hearings of the Presidential Commission on the HIV Epidemic, and we want to thank, particularly, those of you who have been faithful followers of us all along for so diligently attending our meetings.

I am the designated federal official here today. My name is Polly Gault, and in that capacity it is my privilege to declare this meeting open. Mr. Chairman?

OPENING REMARKS

CHAIRMAN WATKINS: Good morning.

Today, our last day of public hearings, the Commission will be addressing the issues surrounding adolescent and adult sexual behavior, and prevention efforts to avoid risk of HIV infection. Also, we'll be addressing the issue of laboratory quality control. We will hear from experts on adult and adolescent sexual behavior who are directly involved in risk reduction efforts. We will also hear from representatives of federal agencies which are involved in funding behavioral research and risk reduction programs. In addition, we will hear from the Honorable Congressman Wyden of Oregon on the issue of laboratory quality control.

In yesterday's hearing, the Commission heard testimony on a variety of issues surrounding the HIV epidemic, including the increasing problem of homelessness and its relationship to the HIV, the problems of HIV transmission resulting from sexual assault, specialized education programs for hard-to-reach populations, and, finally, a presentation by the National Medical Association.

This morning, I'm pleased to turn the chair for this set of hearings over to Doctor Theresa Crenshaw, and I'd like to turn the gavel over to her now as we begin to examine the topics of the day. Doctor Crenshaw?

WELCOME

CHAIRMAN CRENSHAW: Thank you, Admiral.

The Commission has already gone into a variety of areas of human sexuality, which we did in New York a few months ago, touching on sexual orientation issues, hypersexuality, behavior modification and many others. But, in a disease that is

primarily spread through sexual transmission, this issue deserves a deeper look, and, perhaps, it is fitting that our last day is devoted largely to these concerns.

Today we are going to look at the issues in adults and children, particularly, teenagers, in the broadest sense, because establishing the foundations of our understanding of human sexual behavior is really essential to a grasp of what the future has in store. If you don't know what sexual activities or an adult is participating in, the extent of bisexuality, actuarial tables, statistics and mathematical calculations will be of little value. We're going to go into some detail with the relatively brief time we have to go into a very complex issue.

The first witnesses that we'll be hearing from are Doctor Masters, Virginia Johnson and Doctor Kolodny, and, although as I'm sure you all know, they've recently had a very controversial book published, they are not here to discuss the specifics of their book. They are going to lend their cumulative over 80 years of experience in human sexuality to help us understand what that field and what knowledge we have and what knowledge we don't can contribute to the battle to prevent the spread of AIDS.

I welcome all three of you.

PANEL 1: MOTIVATING AND EFFECTING BEHAVIORAL CHANGES IN ADULTS

DOCTOR MASTERS: To the members of the panel, we are most grateful for this opportunity to come and --

CHAIRMAN CRENSHAW: Doctor Masters, could you pull the microphone up a little closer?

DOCTOR MASTERS: We are most grateful for this opportunity to come and discuss these issues with you. Everyone connected with the fight against AIDS now realizes that the virus we call HIV was infecting people before the syndrome of AIDS was clinically recognized in 1981, before it became apparent that an epidemic was occurring.

Unfortunately, as we all know too well, the earliest cases of infection in this country among the homosexual males, and in many ways, efforts to combat this health crisis, to mobilize research support, medical care, public education were impeded to a large degree by antipathy toward the homosexual community.

With benefit of hindsight, it may be said that no one realized what was happening as the AIDS crisis for the gay males

began and veered out of control in the late 1970s. Our interpretation of the epidemiological data, combined with what we know about human sexual behavior, leads us to conclude that the HIV epidemic has not clearly broken out --

CHAIRMAN CRENSHAW: Doctor Masters, if you'll excuse me, we're going to have to adjust those because some of the Commission members can't hear you, and we have the press microphone so close that the auditorium microphone isn't doing you justice.

DOCTOR MASTERS:: Is that better?

CHAIRMAN CRENSHAW: That's much better.

DOCTOR MASTERS:: Okay, fine, thank you.

CHAIRMAN CRENSHAW: Thank you.

DOCTOR MASTERS:: Without definitive research to document this situation, it is impossible to do more than make estimates of precisely what is happening. But, our contention is that in 1987, and so far in 1988, distressingly large numbers of non-IV drug using heterosexuals have become infected with HIV.

Since we believe that it is likely that most of these heterosexuals are, (1) unaware of their infected and infectious state, and, not in long-term anonymous relationships, we think that this presents a critical juncture from a public health point of view, a potential turning point in the nature of this epidemic.

Yet, there seems to be a surprising degree of reluctance to consider this possibility by many authorities in this field, despite the fact that it is clear that no large-scale prevalence studies have been done that attempt to correlate HIV infection with patterns of heterosexual behavior. That is to say, there is almost total absence of data on which one might reliably base the conclusion that the heterosexual community is not becoming involved in this epidemic in larger and larger numbers. Since it is now evident -- from a number of different studies -- that HIV infection is not a rarity among pregnant women, it seems clear that pregnant women who are infected are not all IV drug abusers. We believe that it is imperative to look very carefully at what is happening to the HIV epidemic today in the heterosexual population.

It's disturbing to us that although there is much that is not known about the HIV epidemic, there has been a remarkable reluctance to undertake the studies that would help define its present directions more accurately. For example, to pretend that the current epidemic is defined by counting and categorizing

cases of AIDS, the disease, ignores the biological reality of an infection that often takes place five years or longer from its inception to a clinically diagnosable state. Instead, indeed, by relying too much on examining patterns of cases of AIDS that the medical community is currently seeing, we wind up analyzing what was happening, epidemiologically speaking, some years back. Yet, even with this disease orientation, it is notable that the most -- and, most unfortunate -- that the AIDS-related complex, ARC, is not reportable at present, nor has it been precisely defined by standardized diagnostic criteria promulgated by the CDC. Since there are probably many more cases of ARC than AIDS at present, and since understanding the progression of ARC over to AIDS is important for a variety of reasons, including those related to the tightening of treatment interventions, this diagnostic and reporting vacuum is difficult to understand.

One aspect of sexual behavior that relates directly to the spread of HIV infection has been surprisingly ignored. While it is widely recognized that prostitution is flourishing and provides an important vector for heterosexual transmission of HIV infection in Central Africa, for instance, many public health experts in this country seem to have overlooked the possibility that infected prostitutes constitute an uncontrolled reservoir of HIV infection at the present time in the United States.

Several observations may be of some direct relevance in this situation. First, it is likely that most prostitutes who are currently infected developed this condition as a result of IV drug use, rather than via the mechanism of sexual transmission. Despite this origin of their HIV infection, they are, of course, infectious to others in their sexual contacts.

Second, while it may be true that certain prostitutes, strictly call girls, or women working for the so-called "escort services," may be well aware of the dangers of exposure to and transmission of HIV during their numerous sexual contacts, I think precautions such as using condoms on a relatively consistent basis, it is unlikely, in our judgment, that the majority of prostitutes make any determined effort to follow guidelines for safer sex in the face of this epidemic. After all, prostitution is a commercially driven enterprise, and if customers balk at the use of condoms, prostitutes will generally acquiesce to their demands. It is enlightening along this line of reasoning to realize that many women arrested for soliciting in urban areas do not have condoms in their possession at the time of their arrest. To believe that they have just used their last condom, or are about to replenish their supply, is particularly naive.

Third, it should be obvious that most prostitutes, except the most exclusive, expensive minority, depend on sexual contact with numerous customers for their livelihood. Indeed, it

is not unusual for a prostitute to have eight or ten clients a night, which means that in the course of a year such a person has several thousand sexual partners. Needless to say, this means that there are probably millions of men being exposed to the HIV infection by sexual contact with prostitutes every year in this country. Yet, it is remarkable that there have not been any concerted educational efforts to discourage these men from contact with prostitutes, leaving a decided void in an important public health area.

The fact is that virtually all men who have paid sex with prostitutes have other sexual contacts. These men, who come from all levels of the socioeconomic spectrum, with something of a bias to the upper and middle-class side, thus risk exposing their additional sex partners to any infection, including infection with HIV that have contracted in their contact with prostitutes.

While it would seem that these men would be aware of the potential risk of HIV infection and would take some precautions to minimize the risk, we believe that this is generally not the case. Most men who continue to have sexual contact with prostitutes in this day and age are either denying the reality of the risk involved or deriving sufficiently high arousal by "playing with fire." They have been falsely reassured by news stories, or official statements, that they have interpreted in a convenient way to convince themselves that the risk of heterosexual transmission of HIV is exceedingly small and, thus, is not something they have to worry about.

This must make an assumption, of course, that is fostered by the myth that males cannot be infected by HIV by heterosexual contact with an infected women. While on the topic of prostitution, we would like to make a few remarks about an even less noted facet that has some relevance to the Commission's deliberations. We are speaking now about male prostitutes, the great majority of whom provide sex for pay for other males. Certainly, no one would argue that male prostitutes, as a group, do not constitute an especially high-risk pool of HIV infection. But it is important to realize that most of the customers of male prostitutes are not homosexual men, but rather, bisexual men, many of whom are married, and whose wives do not know about their bisexual activities. These men, after coming in contact with male prostitutes, return to their marriages as potential silent carriers of HIV infection. Yet, this aspect of the current epidemic has been largely ignored. To the best of our knowledge, no concerted efforts have been made on a lasting basis to reduce or eliminate this problem.

The importance of bisexual men in the transmission of HIV infection from the original high-risk groups has certainly been identified.

Bisexuals, regarding their sexual orientation today, are given negative social attitudes toward male bisexuality that have been heightened by the AIDS epidemic, combined with lack of any major groups lobbying on behalf of the bisexual men, it is likely that even more men who engage in bisexual activities are secretive about revealing this side of their sexual biographies to their female partners.

I'd like to talk for a bit about condoms. It is an understandable effort to reduce the risk of exposure to HIV during sexual activity, condom use has been widely advocated. In some quarters, in fact, the enthusiastic endorsement of condom use has been so clearly put forth as a life-saving measure, that it has created a mistaken notion among some health care professionals, as well in the eyes of the public, that condoms are an almost perfect solution to safe sex. We believe that this is a major area that should be reflected on very carefully by the Commission.

Condoms are certainly not foolproof as conceptive barrier devices, which means that they are not foolproof as a means of preventing HIV infection. The fact that the pregnancies occur in 10 to 15 percent of condom-using couples annually is pretty solid documentation of lack of absolute control of the condom.

It should also be pointed out that no reliable research has been conducted or reported as yet to demonstrate precisely how long after their manufacturing date condoms retain their physical integrity. The FDA does not require that condom packages be stamped with effective dates, or some means of identifying packages that have been in storage or on the shelf too long. Consumers are not, by and large, well educated about the use of condoms to prevent the possible sexual transmission of a pathogen such as HIV. For example, most couples who use condoms wait to put them on until just before they begin sexual intercourse. Since there is a distinct possibility that the pre-ejaculatory fluid in the male contains HIV, although incredibly, this phenomena has not been studied to date, to the best of our knowledge, this may pose a risk.

Another practical problem is that many couples who use condoms wait too long after ejaculation to withdraw the penis from the vagina, so that there is often leakage of semen from the condoms as the penis becomes flaccid. On the other hand, we believe that the inherited limitations of condom use are such that if it is known that one partner in the sexual relationship is infected with HIV, and the other person is not, it is unacceptable, indeed, irresponsible, to suggest to them that consistent use of a condom can make their sexual relationship safe.

CHAIRMAN CRENSHAW: Thank you, Doctor Masters.

MS. JOHNSON: The current epidemic poses a particular dilemma for women. Women seem to be at greater risk for HIV infection from a single act of heterosexual intercourse with an infected partner than are men. Women who are infected can transmit HIV to their offspring during pregnancy. Heterosexual women are at risk of being infected with HIV during anal intercourse, while strictly heterosexual men don't have this risk at all, and women have very little way of verifying if a man they are sexually active with has a past or current history of bisexual activity or of contact with prostitutes. In addition, virtually all of the hemophiliacs who have been infected with HIV are male, which means that their spouses and sex partners, who are at risk of acquiring their infection from sexual contact, are almost entirely women. Yet, women are the more or less forgotten constituency in the current epidemic, with relatively little research being done on the psychology of women as it relates to controlling the AIDS epidemic or on education, counseling and treatment needs from the female vantage point.

Minority women, most of whom, incidentally, are not drug abusers, have been particularly impacted by the current epidemic. Yet, little concrete action has been taken to date to recognize their special needs. Unfortunately, there is a paucity of research information available to help delineate racial or ethnic differences in patterns of sexual attitudes and behavior which might well prove to be of significant importance to implementing effective action for these groups in terms of preventing further spread of HIV infection. One other aspect of female susceptibility to HIV infection that has not been investigated very thoroughly as yet has to do with the relatively common presence of inflammation or ulceration of the genital region of the female in association with a variety of conditions, including chronic cervicitis, certain types of vaginitis, internal or external lesions of genital herpes, and similar conditions.

Do such conditions serve as co-factors in determining a woman's susceptibility to infection with HIV via sexual intercourse? Do these conditions provide a more efficient portal of entry for HIV by disrupting the ordinary integrity of the mucous membrane services of the genital region? There is simply not enough information available as yet to allow such questions to be answered. Although this sort of information may have critical importance from a preventive viewpoint, shifting to a topic that affects men and women alike, one aspect of the HIV epidemic that almost all authorities seem to agree about is that knowing a prospective partner's sex history is a key element in protecting yourself from this infection.

The implication is that if you get to know your partner well enough, you will also be apt to obtain an accurate sexual autobiography from this person, and that armed with this information you will be able to make a rational decision about whether or not there is much risk in having sexual contact with him or her.

Unfortunately, our experience in sex research and therapy suggests to us that this process is more apt to be an exercise in self-deception than in uncovering the actual facts. For three decades now, we've been impressed by the number of instances in which couples, coming to us for sex therapy, have kept information about their sexual biographies hidden from one another, even though they may have been married for decades. Indeed, we estimate that in close to two thirds of the couples we've worked with in therapy, not all of whom were married, there was some deception or other practice by one or both partners in regards to full disclosure of their sexual histories.

While it is certainly true that some of these instances involved events that were rather remote in time, such as childhood or adolescent experiences, probably half of the couples we've seen in therapy involved at least one partner keeping secret or lying about a sexual experience outside the relationship that had occurred in the past decade.

It is useful to look in another direction, not from a clinical sample for information bearing on this same point. Here, our experience over three decades in interviewing many thousands of research subjects, married and unmarried, young and old and middle aged, male and female, heterosexual, homosexual and bisexual, may be of some interest.

As a conservative estimate, we believe that more than one third of the people we've interviewed for research purposes have withheld or lied about information about their sex lives from their partners. While the motivations for such non-disclosure are certainly diverse, the point that is germane for purposes of discussion here today is that it is quite likely that a substantial number of couples, probably on the order of half, are not completely honest with each other about their sex lives, even when they have been in long-lasting, non-troubled relationships.

A few additional observations of our's may be of interest to the Commission on this same general topic. Beyond those cases where deliberate deception about their sexual histories is practiced by one or both partners in a relationship, there are also numerous instances where a person answers a question truthfully, but doesn't realize that he or she is inadvertently giving incorrect information. For example, a man may deny that he's bisexual, or has had bisexual experiences,

even though he has had sexual contact with other males during group sex. Similarly, some men who have had same sex experience under certain conditions, as at an all-male school or institutions where there is no access to females, they will vehemently deny that they are bisexual, even though they have clearly had sexual contact with members of both genders. In their minds, however, they have not labeled themselves as bisexual, just as some men who visit prostitutes would not consider that such a practice makes them unfaithful to their wives.

This may seem to be just a simple matter of semantics, but in the context of our discussion of the HIV epidemic it should be self-evident that these sources of misinformation about a person's sexual biography can be just as deadly as those that are deliberate lies.

Furthermore, there's an additional problem that should be readily apparent. Even if both prospective partners are honest in disclosing their sexual backgrounds to each other, there is no assurance that they will each be fully aware of the biographies of their previous sexual partners. This situation, which is compounded by a number of partners involved, means that a woman would not realize, and may well have no grounds to even suspect that the man she had as a regular sex partner last year was, in fact, bisexual if he succeeded in concealing this from her.

Similarly, either partner may have had sex with someone who used IV drugs without realizing this aspect of their life. All of these elements taken together indicate that people generally shouldn't place too much reliance on the probability of obtaining a full and complete sexual history from a prospective partner as the primary means of protecting themselves from possible sexual exposure to HIV infection. This doesn't mean that we suggest that such information is always useless. Rather, we hope it provides a useful cautionary note to be considered by anyone about to embark on a new sexual relationship. Thus, we've suggested that people in this situation strongly consider voluntary testing with open discussion of their test results with their physician to determine their HIV antibody status. In those instances where there is a discordant antibody status between the two individuals, we strongly discourage sexual contact.

On a somewhat different issue, let us make a few observations about the nature of sexual monogamy. This topic is not a new one for us. One of the major contentions in the Pleasure Bond, written in 1975, was that monogamy, a truly committed and exclusive sexual relationship, is not an inferior form of sexual expression, but carries with it the potential for the most passionate, caring degree of intimacy and sexual pleasure.

Although it may come as a surprise to some, who mistakenly believe that we have been advocates of free-wheeling sexual experimentation during our professional careers, what we actually said in the Pleasure Bond may be of some relevance here. Infidelity is a very chancy and unreliable means to use in searching for one's identity. In exploring one's true emotions, in struggling not only to find out what one's deepest feelings, and beliefs and responses may be, but also communicating them to someone else, later in that book, in a lengthy chapter titled, "What Sexual Fidelity Means in Marriage," we spoke out against those, including some clergymen, who were advocating extramarital sex as a means of sustaining sexual interest and variety.

Monogamy in 1988, as in 1975, is not only possible but can be pleasurable. Monogamous relationships need not be lacking in sexual arousals, sexual frequency or sexual fulfillment. In fact, most monogamous relationships celebrate sexuality far more passionately and inventively than is the case among those whose bed-hopping proclivities would seem to provide untold varieties of sexual satisfaction.

This is not just a message we have conveniently discovered in the age of AIDS, but it is a message that clearly bears repeating loudly at this time, because now it is a message that has the potential to save lives. Here we should point out, so that there is no misunderstanding, that monogamy is quite possible and applicable among homosexual couples, just as it is among heterosexual couples.

One question that all of us must consider then is, what are the prospects for motivating people who have not characteristically lived sexually monogamous lives to change their behavior in response to the HIV epidemic? Is it realistic to think that people who have been accustomed to having several sex partners a year, or more than several, will adjust this pattern in the direction dictated by rational prudence in regard to this frightening epidemic?

The answer must come in two parts. The first part is that, yes, such behavior, on a broad-based scale, is quite feasible. While we cannot imagine that it is ever going to be universal, if people become convinced that there is a clear and imminent life-threatening health risk to sex outside of monogamous relationships, many will respond by altering their behavior in the interest of preserving their own lives. We have certainly already seen evidence of such moderation and behavior change is possible, from changes in male homosexual communities in various parts of the country, which, while far from perfect and unanimous, has at least been in the direction that is desirable from the viewpoint of limiting the spread of HIV infection.

On the other hand, it's clear that some homosexual men haven't altered their sexual behavior at all in the face of this epidemic, or have only altered it in part. For instance, by cutting down on the number of sexual partners, or by eliminating anal intercourse from their sexual repertoires, without actually becoming abstinent or monogamous. The response to the HIV epidemic has been quite different among heterosexuals thus far. It seems to us that this is primarily because most heterosexuals have the sense that they are not really at risk, except in the most remote sort of way, as long as they don't have sex with IV drug users, or in the case of women, as long as they don't have sex with bisexual men. Even among heterosexuals who have six or more sex partners a year, there is very little personal fear of exposure to HIV in their sexual activities, which is, in large part, because these individuals have developed a certain sense of distance from the epidemic because they read in their newspapers and magazines, or hear on TV specials that public health authorities are in agreement that AIDS is still primarily affecting the original high-risk groups, that the dimensions to this epidemic haven't changed in any significant way.

Furthermore, there are many mistaken notions that sexually active adolescents and adults seem to share about the HIV epidemic, especially the psychologically comforting but erroneous idea that I can spot someone who is infected by some visual cue. This sense of distance from the epidemic is understandable, but dangerous. Although the Surgeon General pointed out in 1986 that the risk of infection increases according to the number of partners one has, male or female, the more partners you have the greater the risk of becoming infected with the AIDS virus, many heterosexuals prefer to mistakenly believe that this is a gay epidemic, and an epidemic affecting IV drug users, comfortably shrugging off data from Africa and Haiti that indicates that heterosexual transmission is the predominant mode of transmission in those areas, in part, because experts have offered various explanations for the apparent discrepancy between what's happening in America and over there. The general public prefers a position of relative complacency in the face of this epidemic, and this position has been fostered, knowingly or unknowingly, by reassurances from experts that this virus is very hard to catch, that the odds against heterosexual transmission are quite high, and that similar comforting statements, especially, for instance, the citation of blood donor screening prevalence statistics to show that HIV infection isn't happening to any significant degree in the population at large. This leads to the second part of the answer to the question of how possible it is to motivate changes in sexual behavior that will minimize people's risks of exposure to HIV, and this part of the answer is much bleaker, because here we must point out that the longer the public is allowed to believe that heterosexuals aren't really being affected by HIV in any meaningful numbers, the more

difficult and the more time consuming a process it will become to overcome this complacency, and the more problematic it will be to urge people to practice safer sex in response to the epidemic raging above them.

Meanwhile, while the public hears lots of reassurances that few cases of AIDs are occurring in heterosexuals who didn't become infected by sexual contact with a member of a high-risk group, which only tells us, of course, what was happening four or five years ago, not what's happening today, we are missing an opportunity to prevent this epidemic from continuing to run out of control. We are missing an opportunity to save lives.

CHAIRMAN CRENSHAW: Thank you.

CHAIRMAN CRENSHAW: Bob?

DOCTOR KOLODNY:: Before we turn to some specific recommendations for this Commission to consider, we would like to touch briefly on several other points. One is to emphasize that HIV antibody prevalence data, from studies such as blood donor screening programs, are being mistakenly used currently to somehow prove that infection with HIV hasn't made significant incursions into the heterosexual population. Since no meaningful data on the sexual behavior patterns of blood donors has been gathered, and since there is considerable likelihood that the blood donor population is quite different from the general heterosexual population of the United States, this proof has no scientific validity at all, although, it falsely lulls people into a sense of security.

Likewise, the U.S. Military Testing Program data has been cited frequently as another sort of proof that HIV infection is staying within the original high-risk groups, and has somehow stabilized. The actual military test data shows otherwise. For instance, looking specifically at birth cohort groups in the military recruit pool, to permit an analysis of how prevalence rates change over time in a specific age group, such as people born in 1967, for instance. Current statistics, based on a nationwide sample, show a doubling time of 2.5 years for males, and 1.1 years for black females; for young people born between 1962 and 1969. This does not indicate an epidemic that has stabilized. It suggested instead that further spread of the epidemic is virtually certain unless strong action is taken now.

Furthermore, and contrary to popular beliefs about patterns of HIV infection, among teenagers screened nationally in the Military Recruit Testing Program, the ratio of infected males to infected females is a startling 1 to 1, and among 17 year old's females are actually more likely to be infected than males. A second point that we would like to touch on is this: while thus far in the AIDS epidemic there has been a relative

paucity of cases of AIDS in men that appear to have been the result of heterosexual transmission, this may reflect certain historical patterns of the epidemic, rather than what is occurring today in terms of infection.

As others have pointed out, in the early and usually asymptomatic stages of HIV infection, it is more difficult to isolate virus from blood than in late stages of HIV infection, which suggests that the infectivity of an HIV carrier may increase over time. If this is so, than as Burke and Redfield have recently noticed, and I quote, "This factor could have a major effect on patterns of transmission in various phases of the epidemic. The simplest model would be one in which the epidemic is divided into overlapping waves of transmission, with male homosexuals and intravenous drug abusers composing the first wave, heterosexual females the second wave, and heterosexual males the third. Each wave would be functionally separated by the five to ten years that must elapse before an HIV-infected person becomes maximally infectious. To adequate ascertain what future directions may occur in the HIV epidemic in this country, since it seems clear that female to male transmission is commonplace elsewhere in the world, we must have adequate longitudinal national prevalence data."

A third point that we wish to mention briefly is, while it is evident that the sexual transmission of HIV is certainly much less efficient that the transmission of many other STDs, such as syphilis, gonorrhea or hepatitis B, it is all too easy to play a numbers game in which the possibility of infection with a one-time sexual contact with an infected partner looks like a negligible risk.

However, there are documented cases where transmission has occurred as a result of a single heterosexual contact, and likewise, data from infection rates via artificial insemination using contaminated specimens, also support the fact that whatever the statistical probabilities, based on very imprecise estimates that we have today, the stakes are still so compelling, we believe, that it warrants being cautious rather than cavalier in any instance of possible exposure. Unfortunately, once can be enough to be infected.

The final point we wish to make before our specific recommendations is that the current practice of epidemiologically classifying or categorizing cases of AIDs by supposed means of transmission is not an exact science. In most instances, there is no proof whatsoever of how infection actually occurred.

In the interest of time and allowing the Commission to have time for discussion, I move specifically to an abbreviated mention of our recommendations.

Recommendation No. 1: Design and implement a comprehensive national survey to establish a solid base of information about current patterns of sexual behavior. If we are to formulate the most effective strategies for altering sexual behavior in ways that will help control the growth of the AIDS epidemic, an epidemic that is, of course, primarily fueled by sexual transmission, we must have a better set of base line data about contemporary sexual behavior than we now have.

Indeed, as we have pointed out with regret for many years, it is still common practice to refer to the data about sexual behavior collected by Kinsey and his colleagues during the 1940s as the most encompassing and possibly most reliable sample and data set available to the scientific community. Unfortunately, the Kinsey data were methodologically flawed at the time they were gathered and are outdated in many ways today. One possible means of gathering the data base in such a study, with a view towards obtaining a large amount of useful information, while streamlining the efficiency and cost of the project, would be to survey a group of, perhaps, 50,000 people by the use of a detailed written questionnaire, with face-to-face interviews to be conducted on a subset of this group on an every-tenth name basis. That is, it might be determined by sampling experts that interviews with 5,000 of the persons who completed the questionnaire would provide sufficient opportunity for evaluating the information obtained in the written survey alone, and with 50 trained interviewers we estimate that this could be done in two months time.

Certainly, there must be adequate attention to provisions for confidentiality in conjunction with such a project, and this would require deep thought.

Recommendation No. 2: This Commission should urge the Public Health Service and CDC to design and conduct a longitudinal national prevalence study that includes a mechanism for identifying all known risk factors among survey participants. The precise details of such a survey should properly be decided by a team of epidemiologists and sampling experts. We recommend it include testing for other STDs as well.

Recommendation No. 3: The Commission should strongly urge that the CDC formulate a specific set of diagnostic criteria for AIDS-related complex, ARC, and that ARC be designated a reportable condition.

Recommendation No. 4: This Commission should urge that legislation be passed that directly authorizes physicians and other health care workers to notify public health authorities when they are aware of situations in which an HIV-infected person is knowingly exposing another person, such as a spouse, to possible infection with HIV by sexual contact.

Recommendation No. 5: The Commission should be circumspect in the position it takes regarding the use of condoms as a means of providing protection against possible HIV infection.

Specifically, the Commission should recognize that condom use is far from infallible and is not a satisfactory means of guaranteeing safe sex.

We have not attempted to cover all aspects of the current HIV epidemic in our recommendations today, but have restricted our remarks to those areas that are most closely linked to the subjects on which we have given testimony.

We are grateful for the opportunity to have made these statements, and thank the Commission for its invitation to appear and testify.

CHAIRMAN CRENSHAW: Thank you, Doctor Kolodny, Doctor Masters and Ms. Johnson.

I'm going to open the questions for the Commission members, and I'd like to encourage the Commission members to focus their questions on the area of human sexuality so we can make maximum use of our opportunity to have Doctor Masters and company with us.

I'll begin with Doctor SerVaas.

COMMISSIONER SerVAAS: My first question is about teenagers, and spread in heterosexuals?

Have you used, or are you familiar with the most recent work from the Department of Defense, Doctor Burke and Doctor Redfield, on teenagers, and does this corroborate what your predictions are about teenagers and the prevalence in heterosexuals.

The female prevalence is almost as high, I believe, as the male in 17, 18 and 19 year old's in the military applicants who are found to be positive for the HIV virus. Does that corroborate what you have found?

DOCTOR KOLODNY:: Well, we believe that it certainly is supportive of the trend that we believe is occurring, and it is disturbing that the ratio among teenagers, 17 to 19 year old's who are military recruits, is approximately 1 to 1, and, in fact, as we mentioned in 17 years old's, prevalence rates are higher in females than in males. Whether we will really be able to establish what's going on, though, without targeted studies in the teenage population is unlikely, I think.

DOCTOR MASTERS:: It certainly supports the concept that we are seeing increasing dissemination of the HIV in the heterosexual population, particularly in the younger age group, which is traditionally the greatest spreading factor of any STD.

COMMISSIONER SerVAAS: With 589,000 plus teenagers having been tested, and I think they had something like .35 percent positive in the 17, 18 and 19 year old's, is that study large enough to be taken seriously as far as you are concerned? Do you think that we should act on the basis of what we know from that large number of teenagers who have been tested?

DOCTOR KOLODNY:: Well, we should be circumspect certainly in not trying to generalize military recruit testing data to the entire population. Clearly, for instance, there would be some marked differences between teenagers found on college campuses and teenagers who are applying to be in the military.

What we suggest is, of course, we should take this seriously, but it needs to be buttressed with additional studies before we have really defined what the situation is today.

COMMISSIONER SerVAAS: I just was reading an editorial of the piece by Cal Thomas about a woman who lived for 20 years with a man not knowing, and he had a family, they had a family, and then she went to the doctor and found -- his doctor, when he wasn't getting well and she went there, told her, "He won't get well, he has AIDS," and she now is also infected. I think she'll be in the room a little later today, but this woman wasn't told by the physician that her spouse had AIDS and she had a family.

Do you feel that our Commission should recommend that physicians be required to notify all spouses of infection?

MS. JOHNSON: I so firmly believe that dishonesty is probably the greatest deterrent to any kind of control prevention. So, there may be a shock, there may be disappointment, there may be disillusionment or whatever that accompanies this. It is certainly better than being at risk of losing one's life.

COMMISSIONER SerVAAS: So, you feel that our Commission should recommend notification of spouses?

DOCTOR KOLODNY:: Absolutely. That was one of our recommendations, one of our specific recommendations, but I should extend that just one bit, and say that the marriage license by itself isn't all that's required. We think it shouldn't just be spouses who should be notified, but people cohabiting, any known sexual partners.

COMMISSIONER SerVAAS: Knowing what you know about sex, what would you recommend to the Commission about routine or other kind of testing, premarital testing? Do you have strong views about that?

DOCTOR MASTERS:: Yes. We are in favor of premarital testing.

COMMISSIONER SerVAAS: Routine or mandatory?

DOCTOR MASTERS:: Routine.

COMMISSIONER SerVAAS: So, if someone doesn't want to do it, they can be excused.

DOCTOR MASTERS:: Sure.

DOCTOR KOLODNY:: We should say that it would be premature to draw conclusions about the use of premarital screening on the basis of the very limited experience in Illinois and Louisiana to date Even so, we suspect that in an epidemic with an increasing prevalence, a prevalence that will continue to increase until the death rate exceeds the rate of new infection, and it doesn't look like we are anywhere close to that yet, the numbers and the cost effectiveness of premarital screening will become more compelling year by year.

DOCTOR MASTERS:: As the spread of the virus continues, obviously, the cost effectiveness comes down.

COMMISSIONER SerVAAS: Right.

DOCTOR MASTERS:: And the mistake we make is to predicate establishing premarital testing in terms of current cost effectiveness standards, because a year from now those won't be applicable, unfortunately.

COMMISSIONER SerVAAS: We've been watching Illinois, and they have five seropositive individuals, and I think that it has cost them, and I don't know where they get these numbers, $340,000.00 to find the five that they have so far. They predict 50 in the year's time. If those tests cost $4.00 each, as they do for the military through Damon Laboratories, then it would be very cost effective, because one patient discovered could take care of it. If we could only have very inexpensive or free tests -- and, routine.

DOCTOR MASTERS:: It is also true that the more testing we do, the more the cost of the per test is going to come down also. We have to remember that, as far as laboratory charges are concerned.

MS. JOHNSON: It's my understanding that in Illinois the testing is done by private physicians, with a variability of charges being made, rather than a uniformity of charge.

DOCTOR KOLODNY:: And, we would certainly prefer to see testing provided through public health facilities that could be done on a basis more commensurate with the military costs, that is, without the large profit margins and variability in testing quality built in.

CHAIRMAN CRENSHAW: Cory, I'm going to move on.

COMMISSIONER SerVAAS: Thank you.

CHAIRMAN CRENSHAW: We'll probably have time to come back if there are other questions. Doctor Primm?

COMMISSIONER PRIMM: I would like someone, one of you, to respond to why you feel that the nation's blood supply at this juncture is not as safe as it is predicted to be by the Centers for Disease Control, even after the institution of proper testing of donors, and that's quite alarming probably to the American public, and, unquestionably, quite alarming to members of this Commission.

DOCTOR KOLODNY:: Yes. That's a good question, and an easy one to answer. When we wrote our chapter in our book about the safety of the nation's blood supply last fall, the official statements being made from blood banking authorities and the CDC was that the risk of becoming infected with a contaminated unit of blood slipping through, unknowing slipping through the system, was 1.25 million transfused units. Our calculations showed otherwise. Interestingly -- and, showed otherwise, in large part, because of two factors. One, that we recognized, as many others had reported, that the nature of antibody testing left a variable window of infectivity, as I'm sure you've heard many times before, and that in some cases antibodies reaching a measurable detectable level didn't develop for months after the initial infection. In fact, in a paper published in Lancet last October, by Ranke and co-workers, it showed that among sexually transmitted infections, it could take over a year for a person to become seropositive detectably by available testing methods. Actually, the week before our book was published, a study jointly sponsored by the CDC and the American Red Cross in the New England Journal of Medicine, by Ward and co-workers, showed that the mechanisms that we had alluded to, when we had based our calculations on, not only of imprecise testings because of this window of infectivity problem, but also the assertion that we made in our book, without documentation, just based on our knowledge of human behavior, that some gay and bisexual men and drug-using men were, despite the exclusionary criteria,

continuing to present at blood donation centers for a variety of reasons. And, Ward and co-workers confirmed, with, I believe, 11 documented such cases, that this was still going on.

As a result, in their calculations, they changed the risk factor calculation that they used by a factor of close to ten. In other words, they changed it markedly in our direction. Whereas, last year, the government had been saying that there were only some 60 cases a year of infected blood slipping through, the new government figure became about 570. That was much closer to our figure.

DOCTOR MASTERS:: If you think about that, that really means, let's say 600 as a round figure, this really means that at least once, and sometimes approximately once and a half every day, there is a contaminated blood specimen slipping through coverage on a 24-hour day basis.

DOCTOR KOLODNY:: But, the broader question is that these calculations make absolutely no allowance for any errors in the laboratory, or any errors by unit secretaries or clerks inadvertently picking up a wrong unit of blood, when the FDA has had reported to it in a number of instances exactly such errors. And, any of us who have worked on hospital wards, know that sometimes patients are given an incorrect medication, or injection, or an improperly cross-matched unit.

DOCTOR MASTERS:: But, as near as we could come to the approximate figure, there was a contaminated blood specimen used roughly once in every 5,400 cases. To us, that is not absolutely safe protection.

DOCTOR KOLODNY:: But, it certainly is considerably safer than it would have been without the testing.

DOCTOR MASTERS:: Without the testing, of course.

DOCTOR KOLODNY:: We don't want to say testing is useless. In fact, testing is highly effective. But, the blood supply is not absolutely safe.

COMMISSIONER PRIMM: We have had some witnesses to come before us and testify that one way of making the blood supply more safe would be to take blood donors from women, more than from men who are more infected with the virus than, indeed, women.

What do you propose as a way that we could make America's blood supply more safe? Would you -- antigen tests, or whatever kind of testing could take place, that's one question.

The other question I'd like to ask, in view of the recent discovery that saliva contains some substance or enzyme that might render the virus less virulent, or may even be virucidal, it has been reported, how do you now feel about the deep kissing and prolonged, profound kissing, I would imagine described commonly as "French kissing," and more commonly in my community as "swapping spit," how would you describe that now after this information has been made public?

DOCTOR KOLODNY:: Well, let's just comment briefly on the question you asked about the blood supply. There probably is no absolute way of guaranteeing complete safety, and we certainly would not support the recommendation that one only takes blood from female donors. That makes no sense at all.

But, the answer will probably lie in the development of a direct viral test that will permit us to get around the problem of having to test for antibodies, and that will eliminate the window of infectivity problem. There is some progress being made in that direction.

DOCTOR MASTERS:: As far as the saliva situation is concerned, we stand very firm on our concern. The original research on the saliva problem was done in two different laboratories, with very, very few people tested. We don't know to date, whether there is great variation in the concentration of the virus with different people. It is still relatively an unexplored field, and until we have more information, we would be, as we described in the book, sincerely concerned about the open, free exchange of saliva at this date.

COMMISSIONER PRIMM: You also seem to feel that heterosexual transmission at the vaginal mucosa or the cervix is probably more susceptible to infectivity with the virus than, say, the rectal mucosa.

DOCTOR KOLODNY:: No, sir.

DOCTOR MASTERS:: No.

COMMISSIONER PRIMM: No? You talk about the effectiveness of transmission heterosexually in females, just with one intercourse, and you cite two -- in your references, you cite one of artificial insemination in one case, and, I guess, in another case some report from a hemophiliac male to his significant other --

DOCTOR KOLODNY:: No, that wasn't the case. It was in a transfusion recipient with a single occurrence of sexual contact, and the transfusion recipient than died, the paper reported --

COMMISSIONER PRIMM: So, you do not feel that the vaginal route of transmission is more effective than, of course, anal intercourse, the anal mucosa.

DOCTOR KOLODNY:: No. In fact, in our book we make the point quite emphatically that anal intercourse is apt to be considerably riskier, either in gay or heterosexual contacts.

DOCTOR MASTERS:: If you think of the physiology of that problem, with rectal intercourse the seminal fluid is retained over significant periods of time. In vaginal intercourse, a significant amount of that being ejaculated is lost upon separation. We are talking about the physiologic concentration of the virus, so we are more concerned about rectal intercourse than we are about vaginal intercourse.

DOCTOR KOLODNY:: There are a number of different reasons, microscopically, and in terms of the much greater probability of there being some break in the integrity of the rectal mucosa if there is anal intercourse, allowing a direct entry into the capillary bed, rather than just at the surface of the mucosa.

COMMISSIONER PRIMM: What about the receptor sites in the rectal mucosa, and the receptor sites in the vaginal mucosa with the epidermis of the mucous membranes being primarily the same?

DOCTOR KOLODNY:: I would say that the state of knowledge today about exact receptor sites at mucous membrane surfaces doesn't permit us to make exact distinctions. So far as we know, there has only been one report, that in the March Annals of Internal Medicine, that showed that in biopsy specimens of IV-drug abusing women, and the cervical biopsies, there are HIV particles in endocervical canal cells, and the presumption was made that this was able to enter without a direct lesion, a rip or a tear or a sore of some sort.

DOCTOR MASTERS:: The one thing one always has to remember about vaginal intercourse is the high incidence of cervical erosion, and certainly, theoretically, a perfect entree for the virus into the blood supply.

COMMISSIONER PRIMM: Thank you.

CHAIRMAN CRENSHAW: Doctor Gebbie?

COMMISSIONER GEBBIE: You raised some interesting questions for further research, and we've heard some similar questions, not exactly the same ones. It is unclear to me, from reading your work and listening today, the extent to which you have directed those potential research questions into the

research community as contrasted with sort of just shouting them out to the world. For example, you draw a conclusion regarding the total prevalence of the infection in the United States that is considerably different than many others have drawn.

It is not clear to me, from what's been made available, the extent to which you have participated in the modeling groups which have been critiquing those numbers and trying to design better models, yet, when testifying before us seem consistently to come back and say, yet the range of the currently published numbers is appropriate. Have you been participating in those groups, looking at how one draws a conclusion about prevalence?

DOCTOR KOLODNY:: Well, we were not invited to the Coolfont Conference, which was held in mid-1986.

COMMISSIONER GEBBIE: That was not a modeler's group, however.

DOCTOR KOLODNY:: Excuse me?

COMMISSIONER GEBBIE: Well, that group didn't deal --

DOCTOR KOLODNY:: That was a modeling group. That was the original -- that was the place that the original Public Health Service and CDC's epidemiologic data was devised.

We have been speaking with individual epidemiologists. We have not been meeting in a formal group per se, although, Doctor Masters and I have both been serving on an AIDS Task Force in one of our scientific organizations.

But, the variance between our numbers, our estimates, and those of the CDC should be taken as simply variance between two sets of estimates. As we've said in our testimony, we don't have national prevalence data today. We have lots of fragmentary pieces of a jigsaw puzzle.

Everyone has to make assumptions scientifically about rates of progression of the disease, about rates of infectivity in heterosexual and homosexual contact and other such things.

And, it is interesting that although the press has portrayed our numbers as "wildly divergent from the CDC's numbers," in point of fact, in many instances our numbers are relatively close to those of the CDC. The big difference comes in our estimate of the national prevalence of HIV-infected persons, regardless of category, and there are, actually one of the CDC's models that the published in a supplement to MMWR in December comes remarkably close, within 5 percent, of our estimate.

COMMISSIONER GEBBIE: There are large --

DOCTOR KOLODNY:: It wasn't the estimate that they chose, but it is one of their mathematical models.

COMMISSIONER GEBBIE: It is a mathematically possible model, which as far as I know nobody has really latched onto.

In reaching --

DOCTOR KOLODNY:: It's the damped exponential model for equation, and I can give you exact page numbers there.

COMMISSIONER GEBBIE: I have looked at their models rather closely.

Have you published the modeling method by which you arrived at your number?

DOCTOR KOLODNY:: No, we haven't. We're working on presenting that now in journal article form. It's in draft right now.

COMMISSIONER GEBBIE: Do you have a follow-up on that?

COMMISSIONER PRIMM: Not on that one.

COMMISSIONER GEBBIE: Okay.

You indicate a number of questions for behavioral research. Again, I'm trying to identify how you are pursuing those. There is a substantial committee of the Institute of Medicine, I think it get refers to as the "C Base Committee," that has been attempting to devise what ought to be the behavioral science direction that would underpin where we are going with this epidemic.

Have you submitted these proposals to that process? Have you participated in that process? To where are you directing your ideas for such research?

MS. JOHNSON: Well, primarily, we have been lending our support to people, scientists whose focus is in behavioral research and is in the sociology of sexual practice and so on.

Like them, and in our efforts too, we've found funding barriers to it.

From 30 years of being in the field of the science of human sexuality, funding and receptivity from desirable sources has always been a barrier. It certainly has been to Kinsey in

replicating their studies. We certainly have been a part of two major efforts in the past, not directed to the AIDS issues, because they preceded them, but have certainly collaborated in the planning stages. We certainly have met throughout the years with the Kinsey people and with others throughout the country.

You will have to forgive us if we grow a little weary of attempting to do things that we have recognized throughout our professional histories in trying to develop such data that would be available at this time, and certainly, more applicable than 25 or more year old data.

COMMISSIONER GEBBIE: Well, it has been said by many members of this Commission, as we talked with many groups who have come before us, that we uncover a number of areas in pursuit of this epidemic that could have been looked at, or that would help us had we gotten around to them.

So, that is not an unusual piece. The piece that is most difficult for many people in grappling with what you have laid out, is that your ideas and suggestions make a good deal of sense as areas for potential research grounded in your clinical experiences. Yet, I cannot track how that is being addressed into a body of very organized people who are trying to figure out where to go, rather than sort of just broadcast to the world, saying, "Hey, world, here's a problem." I'm trying to figure out how you are proceeding within the organized body of people who are trying to do this.

DOCTOR KOLODNY: Well, I'm not sure that all those people would want to be necessarily identified, but I can tell you that in the last several months we have had, both individually and together, meetings with a number of scientists, a number of laboratory people, a number of behaviorists, raising these same questions, pushing in directions.

Much of this work, as I hope the Commission understands, is outside the realm of our own competence, or our own staff capabilities. We are not, for instance, sociologists. We do not conduct survey research in the broad sense that Kinsey and his team did, and that other teams do. So that, while we have been saying for 20 years how important it would be to have an update of the Kinsey data, to know a lot of things, not just as it reflects on HIV, but other STDs, and other patterns in fertility and so on, that message hasn't been translated into reality yet.

We've met, over that 20 years, with hundreds of groups, including officials of NIMH, officials from other government agencies, and there's never been action taken on it. But, we are currently, and have been for some months, had been last fall in addition, having discussions with various people who are active

in the field, pushing them to try to undertake areas of work that we believe are important that we haven't the time, talent, competence, laboratory support or interest to undertake ourselves.

COMMISSIONER GEBBIE: A number of the conclusions you draw are based on your own experiences working with people over many years. It may be something that has been published and I just haven't identified it. Is that work of your's based in population group experience or is it primarily based in experience of people who come to you seeking help, clinical, like a clinical series based on patients, as contrasted with a community process?

DOCTOR MASTERS: I would say that it covers both. The answer to your question is, yes, both sides. We certainly have had a tremendous experience in terms of people coming for help in terms of sexual disorders. As a matter of fact, just seeing our statistics just recently, we have seen people in therapy from every state of the Union, and 27 foreign countries, so we are exposed to a general cross section of the population in the world in terms of this area, and this is of tremendous import to us.

It suffices to say that what we're trying to do is meet with people who have specific research capabilities and financing, and are acting as consult in just enumerable programs that are being discussed and considered over the period of the last 20 years.

DOCTOR KOLODNY: But, our research work has gone -- has touched on so many different areas, from research in effects of chronic illness on sexuality, effects of drug use on sexuality, infertility, contraception, most areas of reproductive biology, and then widely diverse areas such as psychologic effects of the menstrual cycle, that you are talking about literally tens of thousands of subjects who didn't come to us for help but were recruited in one fashion or another for participation in one of dozens and dozens of different research studies. But, certainly not a representative sample of the population, a group marked by volunteer bias, people willing to participate, and a group marked by, undoubtedly, a higher education level, since many of our volunteers came from the university communities in St. Louis and outside St. Louis as well.

COMMISSIONER GEBBIE: I guess, my last two more questions. First, a lot of what's critical right now, and studies need to be done, do need to relate to adolescents. And, again, it wasn't clear to me the extent to which you have direct clinical experience or direct research experience with adolescent sexuality, or is your work primarily with adults?

DOCTOR KOLODNY:: I guess I'm the one of the three of us who has done the most work with adolescents, clinically and not only related to sexuality, but related to drug abuse work, related to eating disorders, particularly, in teenage females, and related to studies of the timing and sequence of consequences of patterns of pubertal development, and linking pubertal development to our model status and so on.

COMMISSIONER GEBBIE: Okay.

I guess the other -- I'm still puzzling over this, and it's this issue of kind of shouting things out to the world, as contrasted with processing through the system. In many of the documents you've presented, including a couple of issues you presented here, you seem to latch onto the thing that is identified as a very narrow exception in the general scientific conclusion about an area, and then flip that and make that the major point you make with a sort of a Post Script, but everybody thinks some other way. Is this a methodological choice, or are you truly posturing yourselves at odds with 90 percent of the people who have critiqued an area?

MS. JOHNSON: Well, first of all, we don't really consider ourselves as shouting out to the world. We have a 30-year history of having entered a field that made us essentially professional pariahs for a while, because it was such an uncomfortable, such a repressed and unacceptable subject.

We are certainly not the first, and we don't continue to be the only ones, who adopt the method of publishing in book form in order to give and to encompass the experience.

Long ago, on a personal basis, when I would have chosen not to publish at all, not to share with the scientific community, because I was not trained, born and bred into it, Doctor Masters insisted that we use this rather comprehensive and cohesive means of sharing -- can you say "fertilizing the field," for instance, seeding the field, encouraging people, and giving them support in entering the science of sexuality, of addressing the problems there, at a time when, had we gone -- well, in the very beginning there were very few journals courageous enough to publish or willing, because there was too much contention within the editorial boards, though, there were those that made the breakthrough initially.

But, that aside, that's been essentially overcome as we all know now, but the fact is that there is almost no journal that has a timetable that will permit us, or permit anyone, to give both a rapid sharing of material and/or allow the space with which one can give a comprehensive picture.

So, in terms of using the book form, which we don't happen to think, as I stated, means shouting it to the world, but rather, offering it, we have a long history. The Kinsey people didn't go into journals, many other people whose names at this very moment I don't recall, but who are rather significant in this field --

DOCTOR KOLODNY: It's the characteristic mode of publishing in the field of sex research, which is our field.

As to the other aspect of your question, you'll have to give us a specific example of what you mean by our flip-flopping scientific consensus.

COMMISSIONER GEBBIE: Well, I guess the two or three points, one is the blood supply question, although, I think you've clarified some of your point there.

DOCTOR KOLODNY: Actually, what I think you'll find if you read that article, is that the mechanisms described verify virtually everything we wrote.

COMMISSIONER GEBBIE: The other two are the issue of condoms, where I think most people have attempted to be very clear about their lack of guarantee, but about the fact that they are safer than nothing, and when properly used, and there is usually a very long explanation. And, you appear to pick up on the relative unsafety and magnify that greatly.

The other is an issue that you chose not to include in today's materials, but that is the possibilities of transmission outside of the major modes that have been well documented epidemiologically, in which you describe them, and, again, seem to magnify what in general through all the materials is a very minor exception to the extent it exists.

And, I'm pushing for whether that's based on some research data you can put in front of me, that says --

DOCTOR MASTERS: No.

DOCTOR KOLODNY: No, certainly not.

COMMISSIONER GEBBIE: -- everybody else's conclusions are wrong, or whether you are trying to accomplish something different that I just haven't grasped.

DOCTOR KOLODNY: Well, you've included enough different things there that each one would require a very different answer.

But, I think it is safe to say that we are certainly circumspect in wanting people to be aware, scientists or otherwise, of the extent of uncertainty in this area.

And, as to our talking about modes of transmission apart from the major ones, we very clearly labeled those discussions "theoretical risks," and we think there is a clear understanding when you say, "as a practical matter," as we did in several areas, as a practical matter this is not something you have to worry about. However, there are theoretical reasons one should be at least aware of this possibility.

COMMISSIONER PRIMM: Could you make those a little bit more clearer for this audience, and certainly for the public, because I think exactly what Ms. Gebbie is talking about gets to the heart of the question.

When you talk about other modes of transmission, surface transmission, for example, there have been reports that the virus lives for so long on dry surfaces, i.e., toilet seats, for example. Can you comment on those, and I think to give the American public a little clearer kind of understanding of what you meant. If it is only theoretical, state that.

DOCTOR KOLODNY: Well, that was stated very clearly in our book, and if there is any --

COMMISSIONER PRIMM: It wasn't picked up that way, though.

DOCTOR KOLODNY: No, and we're delighted to say that how things were portrayed by the press were often not what we had said.

COMMISSIONER PRIMM: Well, by the way, they are here today, as you know. So, maybe you could be a little bit more --

DOCTOR KOLODNY: That's what worries us.

DOCTOR MASTERS: We'll be able to see how this comes out.

DOCTOR KOLODNY: I think, perhaps, we could summarize it in this fashion. We said, because we've been asked many times, is there a risk to becoming infected if your waiter or a chef in a restaurant has AIDS, is there a risk that you, dining in that restaurant, are going to become infected with HIV? And, we said in our book, specifically, "not unless you have sex or share needles with that person." That's the answer that we gave.

COMMISSIONER PRIMM: Do you hear that, press? Is that clear? Okay.

DOCTOR KOLODNY: The other one was about --

COMMISSIONER PRIMM: Dry surfaces.

COMMISSIONER GEBBIE: Unfortunately, though, again, I'm pushing for --

CHAIRMAN CRENSHAW: Doctor Gebbie, we're really running close on time, and I've gotten notice that the Admiral would like to --

COMMISSIONER SerVAAS: I have a follow-up on Doctor Gebbie's. I do have a friend here, Doctor Engleman from Stanford University, who says --

COMMISSIONER PRIMM: Ms. Chairman, we need that question answered, Mr. Chairman.

CHAIRMAN CRENSHAW: The base question was not answered yet. He's not finished yet.

COMMISSIONER PRIMM: Could we have that question specifically answered?

CHAIRMAN CRENSHAW: Cory, let Doctor Primm finish his question.

COMMISSIONER SerVAAS: Sorry.

CHAIRMAN CRENSHAW: You can have a brief one. We'll go to the Admiral and wrap up so we don't run overtime, so just wait for a few minutes. Go ahead, Doctor Primm.

COMMISSIONER PRIMM: No, it was Kris' question.

COMMISSIONER GEBBIE: We're both kind of pursuing some of the same points.

COMMISSIONER PRIMM: That's right.

DOCTOR MASTERS:: The specific question.

COMMISSIONER GEBBIE: Well, I'll try again.

DOCTOR KOLODNY: Let's finish the answer that Doctor Primm asked, since he phrased it very plainly, and I think he's looking for a plain answer.

He alluded to the fact that some research studies have showed that the virus is capable of surviving on plastic, or metal surfaces, outside the body for varying lengths of time. We

discussed this and cited this paper in our book. As to the practical reality of the risk of contracting the virus from a hard surface outside of the laboratory environment with highly concentrated solutions of the virus, let us just say that we traveled here by public transportation and we all used the toilets in those areas, and that should address the practical aspect of the risk. We do not suggest for a minute that people not use public restrooms, but we do suggest, if a public toilet looks to be contaminated with suspicious substances, blood, other materials, we wouldn't have used that 15 years ago in the time before AIDS, and we don't suspect that anyone would really use that now. This is common sense. No one is claiming that the virus jumps off a surface and bites you.

CHAIRMAN CRENSHAW: Doctor SerVaas, very quickly?

COMMISSIONER SerVAAS: Okay. No, less than the Director of the Stanford Blood Center at Stanford University is saying that he agrees that the number of persons that we estimate, 10,000 to 12,000 infected from blood transfusion is way too low, and he says he has no idea how high the number may be, but he's in complete agreement that we should be testing the people to find out who have had blood transfusions in the last ten years. How do you think we should go about doing that?

CHAIRMAN WATKINS: Madam Chairman, I really object to the question. We are on sexual behavior. This is not a time for talking about, in my opinion, the blood supply. We will have plenty of time this afternoon.

COMMISSIONER SerVAAS: But, it was discussed with Doctor Gebbie.

CHAIRMAN WATKINS: And, I haven't had an opportunity to ask questions. We're five minutes from completion, and I really want an opportunity to talk to the witnesses, which I have not had the chance to yet.

COMMISSIONER SerVAAS: I'm sorry.

CHAIRMAN CRENSHAW: Admiral?

CHAIRMAN WATKINS: I want to follow your own direction. Thank you.

Let me follow up again, Doctor Kolodny. We had testimony from some of the best neurosurgeons in the nation that came before us the very day that there had been a publication of a study done by competent people, published in the press, which said that the first thing we could detect is early neurological damage on HIV asymptomatics.

It caused considerable confusion in the nation, and, in fact, the Department of Defense moved out aggressively in some cases to try to establish a policy of downing all aviators.

The witness stated that before they would ever down an aviator who was diagnosed as HIV positive and asymptomatic, with no other clinical condition, we would like to know, how old he is, when he had his last drink, and I'd like to know 42 other questions first.

We aired that very thoroughly on national television, because we felt it was important to allay fears of studies projected into the scientific and the world simultaneously without peer review.

DOCTOR KOLODNY:: Well, that study was peer reviewed. It was published in the paper by Grant and co-workers, it was published in the Annals of Internal Medicine.

CHAIRMAN WATKINS: Put in better context later, but still, refuted by some of the best people in the nation that find that there is no compelling evidence that supports the asymptomatic HIV case being the first signs, as you can detect that early, and that that's something that's here now. It certainly was not presented to this Commission.

There is an article by another doctor in Cosmopolitan magazine that is the very opposite from your recommendation, causing again confusion in a society that's already confused about the epidemic.

Your book came out, why the urgency to get it out weeks ago I have no idea, but it seems to me that in the early stages of an infectious disease such as this, where we are trying to get a baseline of information, establish a national strategy, listen to the best minds in the world, including the World Health Organization, and strengthen that relationship with the Global Program on AIDS and so forth, that it's time for a steady hand on the tiller.

And, I'd just like to know your reason for why this information had to move out so expeditiously to the public in the face of severe criticism that you've subsequently received, and that's perfectly legitimate in scientific research work, and I understand that. But, right now we ought to all be pulling together to try to collaborate our information and make sure that it's placed in a perspective, that does not regenerate the dust in the air that has so surrounded this epidemic to date.

So, I want to ask you, what was the urgency? Why didn't this information it go through a better process, because you really did come out with some rather marked changes from the

base scientific data that people like Doctor Fauci, and Doctor Krim, and Doctor Osborne, and Surgeon General Koop, and many others who criticized your document, have been espousing throughout the nation.

So, I'm just confused about that. I don't want to get into the details of technical research, because that's not my bag, but I do think that at a time like this we need to be talking a lot closer together on these kinds of things because I do think that with something as significant as your book, and with the credentials that you have generated over the years, that it's even more important that there be an element of solidarity, among the scientific and medical communities that come together and chat about these things in their own circles first.

MS. JOHNSON: Well, I think first and foremost, at least in my mind, it was an attempt to counteract an earlier reluctance, an earlier absence of openness, and honesty in collaboration.

I think that if there was the potential for "panic in the streets," as a result of this book in any way, shape or form, it was certainly not intended. It was intended as a catalyst for concern.

We, in a clinical setting, in a research setting, and as just human beings with, I presume, credentials, we're asked all the time, "What can we believe? What is right?" I think that your point is perfectly placed. I think collaboration and some kind of reliable basis for people to believe in, but I don't think that we would have been, in our minds, necessarily, in agreement with you, had it not been for previous years when there were so many statements made that invited the people, the population in general, to feel complacent. I think we were a counteracting force, and I feel it was necessary that someone do it, and we have a history of assuming the role of catalyst, just to bring the issue forward.

If it had not been for the previous attitude of, there, it can't happen to you if you are heterosexual, or if you are one of various other groups, then I don't think the reaction would have been as intense. But, I think it's better that this information be presented now, and a cautionary attitude be institute rather than drawing conclusion with dire results later on.

CHAIRMAN WATKINS: Are you saying you tried to get it through the system and you could not?

DOCTOR KOLODNY: No, no, no, that's not what we're saying at all.

MS. JOHNSON: No, not at all.

DOCTOR KOLODNY: With all due respect for both the spirit of the comment that you made and for your own efforts over this last year, in particular, on behalf of bringing a degree of unanimity of outlook to the AIDS epidemic, which, at the leadership level, and at the policy implementation level is very much called for, we're sure.

With all due respect for that, and not meaning to sound critical at all, the process of science, we believe, is not and never has been served by looking for unanimity of opinion. The process of science has always been served by allowing people to speak forward on varying interpretations and, indeed, we look at the same sets of data that the CDC looks at. We believe that a different interpretation should be made of some of that.

We are, and have been for several years, and have been talking for several years to people such as Mathilde Krim, about the fact that we are dismayed that no research was sponsored by the government to specifically identify the prevalence or incidence of infection with HIV in heterosexuals documenting their patterns of behavior. Believe me, we would have loved to have not been the ones to conduct that study.

We were aware of reports circulating in the scientific community where scientists were saying things privately, off the record, in corridors, over cocktails, that they were not willing to say in front of the microphone or in front of the press, and some of this was eventually reported.

A year ago, for instance, most government experts were remarkably silent on the rate of progression from being infected with HIV to ultimately becoming ill with AIDS, the disease, or other immunologic abnormalities. Now, the press is rather uniform in the fact that most scientists seem to think that a majority of infected people will eventually become ill.

Why wasn't the public told this a year ago when so many government scientists, so many leading public health figures, were privately voicing such opinions, and were wearing two faces, in effect?

So, we believe that we have a perfectly valid reason for presenting a different view, and a view that we admittedly state may be wrong, we hope it will be wrong in lots of way, but a view that is undertaken with a philosophy in part that in dealing with a fatal epidemic, with lots of areas of uncertainty, isn't it prudent to be somewhat cautious in one's estimations, rather than to be overly optimistic?

CHAIRMAN WATKINS: Well, I think you have some good points, and certainly disagreement is commendable in this area. I'm not saying that it should not be. I just feel that a disciplined approach and an acceptance in a profession of moving through channels is proper, and if the channels fail to see, it seems to me that's a perfectly legitimate time for you to go public. But, it seems to me, from your own colleague's point of view, to abandon a system that's been in effect for a long time, you know, I am not an expert on medical ethics, but it just seems to me it's appropriate or scientifically ethical to go through the system. Once it fails, and you feel very strongly that your data supports such things as the 3 million (infected with HIV) conclusion, which wasn't clear.

DOCTOR KOLODNY: No, that's not data, Admiral, as you know very well.

CHAIRMAN WATKINS: Well, the impression, though, is data. The perception of things is very important in the front end of a disease like this.

DOCTOR KOLODNY: But, why is it different for the CDC and for us? The CDC says their estimate is this, we say our estimate is this. It's not fair to say that our's is inferring data and their's isn't.

CHAIRMAN WATKINS: No, it isn't, but it would have been nice to have it gone through the standard peer review, and appeared in the JAMA, or into the New England Journal of Medicine first, or a similar publication.

DOCTOR MASTERS: But, there would have been no way to present our total picture by publishing in JAMA, or publishing in The New England Journal, as you are aware, Admiral. We wanted our concept presented as fundamentally as catalysts to improving the concerns and the facts.

CHAIRMAN WATKINS: But, did it catalyst the scientific and medical community? My readings of the comments were that it did not catalyze them, but it did catalyze the American people.

DOCTOR MASTERS: Well, all I can say is --

CHAIRMAN WATKINS: And, I don't know what that means right now at this stage of relative ignorance on all our parts.

DOCTOR MASTERS: -- I have a sneaking suspicion that there is going to be much more effective research done.

CHAIRMAN WATKINS: Let me close out with one broader question, and I would like to address this to Doctor Masters and Ms. Johnson.

One of the things that I'm sure you are thinking of, but it doesn't appear here, is that when we are looking for base-line data on contemporary sexual behavior, let's assume we have it today, what do we do with it? If we take a picture of the nation today and what it's doing, and then we want to effect behavioral change in a positive direction, it seems to me we have a much broader issue at hand. What is the baseline of knowledge among the young people or others that we're going to lean on in order to effect the behavioral change? If it's sexual therapy, we're dealing with a very sophisticated thing. If it's fundamental understanding of our own human biology, it's another thing.

Now, I work with groups of people in academia and the medical profession, and business and others, who are very concerned, as are many witnesses, that this nation has no solid baseline of public education on the subject of health, health promotion, our own fitness, our own human dignity, and our bodies, which are unique, to put this kind of thing in context.

DOCTOR MASTERS: Agreed.

CHAIRMAN WATKINS: We have HIV and poverty directly linked. We have HIV and the underclass directly linked. We have HIV and illiteracy directly linked. We have HIV and lack of early health care, and access to health care, directly linked. So, it raises a lot of other issues, it seems to me, when we get into the subject of behavioral change, which is what this topic is all about. So, once your base line is obtained, I don't see the longer objective of how we get this nation on its feet in health.

DOCTOR MASTERS: The only --

CHAIRMAN WATKINS: And, I think we've got --issues substance abuse. Where do you put it in relation to sexual behavior? You have to put it in the minds of the young people growing up at the right level of maturation. So, it's more important to me to find out what is the baseline of our own understanding of our own human biology in the nation. Do we have a life science's continuum concept from preschool all the way up?

Now, if I saw that coupled with this, I would say, maybe we have a strategy and a package moving together that makes some sense in the nation. And, it seems to me that a prestigious group like you should be encouraging that as an integral part of this, so that it doesn't appear to be an appendage. Also its good to have baseline from old Kinsey data all for itself. And, that's what comes through in your recommendations. Would you comment on that?

MS. JOHNSON: Well, Admiral, people have to believe. They have to believe that what they are hearing is valid, is honest, and certainly, there has been a lot of distortion. But, I think there is something that even we forget, the subject of sex.

If I understand correctly, even the mailing of a pamphlet or brochure; there is a general mailing, which I understand is now going to take place. I further understand that the pamphlet was shunted aside for a while, primarily because it was deemed to be -- this is coming from the Surgeon General -- because it was deemed to be too explicit.

So, we've always had that problem, and if we don't have baseline data, -- we really don't know what we don't know yet, but we are still all trying.

It hasn't been so long that we could even talk in anatomical terms, and there is still great groups of people throughout our population that won't listen, that are so affronted by, or so discomforted by, direct information.

Fortunately, the targeted group that you mentioned, the young people, are, by and large, not quite that reluctant to listen, but they have to believe and they have to trust the data.

The greatest models for the young and the very young, and we are talking about not very young, and certainly education at that level is not our expertise, there is a limit to how young we can start, but the greatest models are parental, or the adults in that young person's or those young people's lives. And, something that we learned in terms of sex education early, early on, you can never educate one generation at a time. You have to educate simultaneously the young and those who are the active adult practitioners. You must do it dually.

I don't know whether this goes to the heart of your question, but the effort of so many people committed to this field, and doing so when it wasn't popular, it's never been popular, it's not popular now, and with the subject of sex, you find that so many things you want to do are not acceptable, or if you develop the information, the receptivity to it is also very reluctant.

CHAIRMAN WATKINS: I understand that. I'm just trying to bring out a larger issue that I think we have to face, because the sexual behavior treatment as a specific item becomes very difficult for the American people to absorb that.

DOCTOR MASTERS: Exactly.

CHAIRMAN WATKINS: What are you talking about? Are you talking about condom vending machines outside the third grade homeroom? What are we talking about? So that, in the minds of individuals, the perception becomes very complex.

I'm talking about much more fundamental understanding of our bodies, so that when we talk about substance abuse, or nutrition, or teen pregnancy, we have a much better understanding. So then when we look at sexual behavior, we can begin to relate it to the human biological aspects of this thing and do something about it in an orderly fashion in the nation.

And, we've been told by very competent people in public health that they evaluate our public school system in the nation, and health education, health promotion is a D- for a nation --

DOCTOR MASTERS: I agree.

CHAIRMAN WATKINS: You agree.

So, I'm just saying, it seems to me that, because of your prestige and your stature in the nation on this subject, I would encourage you to reach to the larger issue in parallel with what you are trying to do, so that we can all understand it and begin to put it in the proper repository in the nation, because I don't think we know how to deal with it right now.

MS. JOHNSON: I agree with you.

CHAIRMAN WATKINS: So, if you get your base-line of data, I'm afraid we're going to be in the same dilemma, if you had it today, as we were yesterday. You'll know a lot more, and the data is a lot cleaner, but we don't know what to do with it still.

DOCTOR MASTERS: Admiral, we couldn't agree with you more.

MS. JOHNSON: Could I digress --

CHAIRMAN WATKINS: I needed that, Doctor Masters. Thank you.

MS. JOHNSON: -- could I digress for just a second in order to present somewhat our philosophy, digress into the infertility field.

For all of the work that Doctor Masters has done, and others, as pioneers in the infertile couple, the sterile couple, he developed a program early on which simply talked to the couple for just one 45-minute period at the beginning of their request for help for conceptive difficulties.

During that talk, he told them simply when to have intercourse, how to have intercourse, and how often to have intercourse, and sent them home to try for three months. I will let him tell you the statistics of a large population of these people.

DOCTOR MASTERS: Just very briefly, with thousands of cases just being taught how, when, how frequently, and nothing else, no work up, and given three months to try it, one out of every eight to nine infertile couples conceived within a three-month time period.

MS. JOHNSON: So, that's the way we try to present material. We don't get a lot of cooperation in doing that, and, that may be we haven't shown a deal of evidence of having done it successfully, vis-à-vis the AIDS concerns, but that's where we are coming from all the time, and being party to, and supportive of, and encouraging of anyone and everyone to do the things wherein they have expertise. We join them, we do what we can for them, but we are always in the position of trying to simplify and thus appeal to those people who say, in essence, you know, the very young, we're invincible, it won't happen to us, or who takes very seriously the earlier messages that said, in effect, if you are heterosexual you are not at risk, or the whole list of the reassurances that came out.

I think that is our first line of attack as we sought to be catalysts, to disabuse, not to panic, and not to upset, or develop unnecessary concerns, but to try to make amends for those reassurances that were misplaced.

CHAIRMAN WATKINS: Thank you.

CHAIRMAN CRENSHAW: I want to thank you very much, and to move on to our next panel, I won't ask you a question, but I'm just going to make some very brief wrap-up comments. First of all, I appreciate what you are saying, in that if the attention of the world does not acknowledge that heterosexual transmission is a significant problem, and if men don't think they can get it from prostitutes, you simply can't develop programs or implement programs that no one thinks are relevant.

So, dealing with the issues of, is it a problem, is it not a problem, is terribly important in order to get the attention of the scientists and the people.

And, I will also express the fact that in my experience, and in the experience of many other sex educators and therapists, who attempted to move into this field and contribute their expertise, the first comment I heard, and most frequently, from the most people, was, "What does a sex therapist know about AIDS?"

I always found it amazing that intelligent people would raise that issue. Obviously, the world didn't know a great deal about it, but sex therapists knew a great deal about the major mode of transmission, and how to intervene.

So, I think we are at a point now where we are able to put aside for the immediate moment the issue of how great is the scope of HIV infection in the heterosexual community, because everybody seems to agree that it is a significant problem for heterosexuals. The Public Health Department does, the Surgeon General does, and you do, and I think now, perhaps, we can do just what the Admiral is suggesting, and, that is, begin pulling together with more collaborate efforts to work on exactly those critical issues which I think have been lost, that the Admiral's last question highlighted, and, that is, how do we get the job done in the best way, and where do we find enough common ground that we quit tugging war with one another and all pulling in the same direction.

So, I want to thank you very much for being here, and taking a little further heat for the work that you are doing and continue to try to do.

DOCTOR KOLODNY:: Thank you very much.

CHAIRMAN CRENSHAW: I'd appreciate the next panel coming forward.

PANEL 2: MOTIVATING AND EFFECTING BEHAVIORAL CHANGES IN TEENAGERS

CHAIRMAN CRENSHAW: We're going to begin now to focus on our adolescents in additional depth. We had the opportunity to pay some careful attention to the potential problem in adolescents in some depth yesterday with some very fine witnesses. And, I think that this panel has the opportunity now, with virtually every word they speak, to respond to the Admiral's concerns that he just expressed, because this is why we are here today.

Basically, the question is: how do we get the job done? What can we do? What is the wisest course or action, and what are some of the questions that still exist on how to get some of this very, very challenging task met. I think that all of us here today would agree that teenagers are, and probably have always been the ultimate high-risk group, and our concern for them in providing an uninfected generation is increasing as we learn more about what is happening with relation to AIDS transmission.

So, I'd like to hear first from Doctor Wendy Baldwin, who is going to give us an overview.

DOCTOR BALDWIN:: Thank you very much.

I am Doctor Wendy Baldwin, Chief of the Demographic and Behavioral Sciences Branch of the Center for Population Research, the National Institute of Child Health and Human Development.

Would like to put my comments a little in the context of what our Institute does. We are deeply concerned with issues regarding AIDS, issues regarding contraception, sexual behavior, contraceptives themselves, the care of women who are HIV positive and pregnant, the care of children who are HIV positive, and behavioral changes that are necessary to deal with HIV infection.

In my program, we have studied adolescent fertility for many, many years, and we believe that adolescents do deserve special attention regarding HIV infection. While there are relatively few cases of AIDS among adolescents, only 257 as of the end of April, the long latency period makes it quite likely that a number of the cases that we see in young adults were actually contracted while they were adolescents.

Adolescence represents a very specific time in life. It is a time of from childhood to adulthood, and a time of trying out adult behaviors. One is good. Some of them are taking a job, for example. But, others, for example, drugs or alcohol, are hazardous. Some high-risk behaviors, such as IV drug use are specific risks for HIV; other high-risk behaviors may involvement sexual activity. Certainly, sexual activity is one of the adult behaviors that is frequently begun while people are adolescents, that is the area that I want to focus on that is the most relevant for my program.

If we ask whether teens are at risk of HIV transmission through sexual activity, we do have some data to study. We have been collecting data to determine the proportion who are sexually active while teenagers. In 1982, we saw that 45 percent of teens, aged 15 to 19, were sexually active, and that about a fifth of those who were only 15 years old are sexually active. The rates, depending on the study, are 15 to 20 percentage points higher for boys.

We have spent a lot of time considering the time trend, in sexual activity, because in 1982 it looked like the proportion was beginning to decline a little bit. We have regarded these data from several perspectives. First, can we believe the data? Yes. We have data collected from a number of different surveys by different organizations, at different times, and with some different questions, and they give remarkably similar patterns and estimates of sexual activity. Second, when

study at the trends, we have asked what happens if we look at birth cohorts, because we know there have been changes during the 1970s, and we have found that if there are any declines in sexual activity among teens, they seem to be concentrated at the older ages. In other words, if you survive to be 17 or 18 without becoming sexually active, in the last few years we have seen a slight decline in the proportion begin who go on to sexual activity before age 20. Unfortunately, we still see increasing rates of sexual activity among young teens, and for most of us that is the most troubling group. Finally, while we have data on the proportion who are sexually active, we do not have data on sexual practices, so we cannot tell you the proportion who engage in, for example, anal or oral sex, which might constitute a higher or a lower risk of HIV transmission.

One of the ways we look at adolescents in regard to their risk of HIV transmission is through condom use, because, clearly, although one can debate how effective they are, condoms do offer some measure of protection against sexually transmitted diseases, HIV. We see that of the teens who use a method at first intercourse, which is about half of teens, half report using the condom. But, teens, like adults, move rather quickly away from the condom and to methods that are less intrusive to sexual activity, and offer better protection from pregnancy, such as oral contraceptives. So, when you look at a representative sample of teenagers and ask, what is the method they are using now, only 11 percent are relying on the condom. That's a little bit higher than for adults, where it is only 7 percent, but it is not very high.

The lack of protective behavior can be seen when you look at sexually transmitted disease information. CDC estimates that 2.5 million teenagers a year contract STDs. I have looked particularly at gonorrhea rates, because they are increasing over time, and it is rather troubling to see that among women, the rates for teens are almost as high as the rates for young adults. That is particularly troubling, because we know that only about half of teenage women are sexually active. So, if you adjust for the fact that fewer teens are sexually active than young adults, you see that the risk of contracting gonorrhea is actually highest for women when they are teenagers.

In a way, that is counter-intuitive, and it does not match the data for men. So, you could ask, what kinds of explanations do we have for increased risk among young teens? First, if you look at the literature on cervical cancer, you could conclude that, perhaps, teens are at more risk of infection because of their age. The teenager may be facing a situation where the cervix is still in a rapid state of growth, and that can make her more susceptible to infection. This would explain the age and sex patterns that we see for gonorrhea infection.

Second, as I've already pointed out, while the rate of condom use is a little higher for teens than adults it is still very low. A rate of only 11 percent for teens, indicates a low level of protective behavior.

Finally, we have looked at the number of partners that teens report, and here the data show that half of teens who are sexually active, report only one partner. Few, only 10 percent, report six or more partners. We have also looked at data for unmarried women in their 20s, and we find basically the same pattern. We find that most women report very few partners, and a few report a large number of partners.

I am a little concerned about the emphasis on number of partners, because, in fact, one infected partner is a serious risk; and for teens who are in areas where infection rates are high and where their male partners are at high risk of being drug users, we may be doing a disservice if we focus on a large number of partners as defining the risk condition. In fact, it is exposure to anyone who is HIV positive that is a risk condition.

When we look at the STD data and contraceptive data, it is certainly clear that adolescents are a risk group for HIV infection, and I have tried to make this overview of what we know in terms of behavior and the relationship between age and these risk conditions rather brief, because I think that now we need to look to the future to decide what we are doing.

We know we can collect data on some very important indicators that we need now to address HIV infection. Unfortunately, we also know there are rather significant gaps in what we have collected.

We need better data on sexual behavior among adolescents to guide intervention efforts. Research on sexual behavior is an integral part of attempts to modify that behavior. This is very complex behavior, especially among teens who are just beginning in sexual behavior, and we not want to start with too simplistic a view of what that behavior is or what it means.

Adolescents need accurate information, services, and the skills to make sound decisions regarding their sexual activity. We have seen increasingly that teens are avoiding early marriage, and so the period of time between puberty and marriage has been lengthening quite substantially. This means that teens have a long period where they must continue to make decisions about their sexual behavior. These decisions frequently have many effects, not just unwanted pregnancy, but, obviously, STDs, and now the possibility of HIV.

We are, in particular, focusing on the development of large, nationally representative studies of sexual behavior for adolescents and adults. These are not simply studies that will let us count how many people have done engage in specific risk, behaviors, although that's obviously important as well. These studies will put behavior in a context of what motivates the behavior; this will help us identify strategies that could help us address how to help people modify their behavior or manage that behavior so that they bear fewer of the negative consequences that we understand can happen.

These are not studies of special populations, although special populations (such as runaway and prostitutes) are very important. These are studies of the general population. They are important in order for us to understand how HIV may move through our population in general, and not just through specific groups.

There is an ongoing need for research on sexuality; research that, by and large, has not taken place. While we feel that adolescence is a particular time of interest and importance, it must be a coordinated program of research that includes adults as well.

The development of therapies and preventive strategies for AIDS is an extremely important part of any AIDS program. However, even with such strategies, we still have many, many reasons to try to help people manage the multiple risks that may be associated with sexual behavior, and that is the thrust of my program. I'd be happy to answer questions from the Commission.

CHAIRMAN CRENSHAW: Thank you very much.

CHAIRMAN CRENSHAW: Doctor Carrera?

DOCTOR CARRERA: I appreciate this opportunity to be here and participate on this panel.

We are all deeply concerned about the human immunodeficiency virus and its impact on the lives of so many people in our country.

My particular work is with black and hispanic adolescents, and I'm troubled about how we, as a nation, are addressing the issue of HIV as it relates to young people.

In this connection, I'd like to make a few brief statements and a recommendation for community-based action.

The behaviors that especially put young people at risk of HIV infection, unprotected sexual intercourse and intravenous drug use, are common among American teens. About half of all

adolescents have intercourse by their late teens, and there is evidence to suggest that only 10 to 15 percent regularly use condoms, which affords significant protection against HIV and pregnancy.

Federal health officials estimate that one in seven teens currently has a sexually transmitted disease. Drug experts estimate that more than 200,000 high school students have used heroine, several hundred thousand more, perhaps, as high as a million, have tried cocaine, stimulants or other drugs which are injected intravenously. Crack use creates a climate in which HIV infection can be easily spread. Alcohol use is rampant among American teens. Alcohol use impairs judgment and reduces impulse control, also creating an environment for HIV infection.

Drug use and greater rates of unprotected intercourse are higher among school dropouts. School dropouts approach 40 to 50 percent in New York City, and are estimated at 30 percent nationally.

Geography also increases one's risk. In some New York City neighborhoods, for example, epidemiologists estimate that as many as 20 percent of adult males may be infected with HIV. If a young person has his or her sexual partner in this neighborhood, the chance of infection is high, and while certain groups of teens are at high risk, no wall divides those at risk from others.

Young people who use drugs may have sex with those who do not. Those who engage in prostitution for economic or drug reasons may also have steady boyfriends and girlfriends. The prevalence of HIV infection is higher in urban and minority communities, but, of course, now every state has identified persons with AIDS.

While few teenagers are currently infected with HIV, all that is known about the epidemiology of AIDS suggests that young people could become the next group to experience the devastating impact of this epidemic. For no group are opportunities for prevention greater.

So, quite literally, for some teens exposure to HIV infection is a decision away. To have sexual intercourse or not, to use a condom or not, to try shooting drugs just once or not. Almost every teenager faces these questions at some point. Since their lives depend on what they decide, all teens need to know how to protect themselves against HIV infection.

How successfully health, social service professionals and educators serving young people meet the challenge of AIDS prevention will determine the course of the epidemic in the years to come.

The HIV problem is a very complex problem, and it requires a complex intervention. Simple solutions do not solve complicated problems. Slogans like "Teach young people to say no," or, "It's okay to say no to drugs or to sex," have a nice ring to them, but as one observer pointed out, "They are as effective in prevention of adolescent pregnancy and drug abuse as the saying "Have a nice day" is in preventing clinical depression."

I think we need to do more. I think that we need to look at the climate in many of our communities. What is happening today, especially in the inner city, is that young people are growing up in a climate of fatalism, of hopelessness. There is an institutional racism that affects young people in a dramatic way in this country. It leads them to take risks.

What we need to do in our programs is, not only provide them with explicit, and clear and ongoing education at every opportunity in the schools and in the communities, but we also must develop community-based programs which seek to provide young people with opportunities to develop hope in their lives, so that they can move from hopelessness to industriousness, and the only that happens is by helping them develop a realistic life agenda where it makes sense for them to use a condom, where it makes sense for them to avoid risky behavior, where it makes sense for them to continue in school and to be productive through employment.

We, in New York City, have a program in the Children's Aid Society which initially was directed towards pregnancy prevention, using a multiple intervention holistic model to get young people to move from fatalism and hopelessness to better feelings about themselves. In four years, we've had two females who have been pregnant in central Harlem. We have 217 young people in our program, 215 remain in school.

In one community center, 89 of the teens out of 100 who are being served have bank accounts at the Carver Federal Savings Bank. All of those young people come from families who are Public Assistance dependents.

What we need, I believe, in order to deal with this program, with national programs for HIV prevention, not only education, but also social policy change which affects young people, not only below the waist, but above the waist.

CHAIRMAN CRENSHAW: Thank you, Doctor Carrera.

CHAIRMAN CRENSHAW: I am going to break tradition here for a moment, since we started late and I know Dr. Carrera needs to leave early.

So, would like to invite any panel members who would care to direct questions to Doctor Carrera at this time so that we are sure that we have the opportunity to hear his response.

Doctor Primm?

DOCTOR CARRERA: I appreciate that.

COMMISSIONER PRIMM: Doctor Carrera, first, I want to commend you on the holistic program that you are running in East Harlem and, of course, Spanish Harlem and Harlem itself. It is remarkable that such a program even exists, and with such success with all the other difficulties that face the people in that community.

You discussed institutional racism, and a holistic program.

DOCTOR CARRERA:: Yes.

COMMISSIONER PRIMM: I think that what you have recommended here is a model that could be replicated in other parts of this country with the kind of success that it has demonstrated.

I don't know whether there is any way of expanding it or the like. Have you inquired about further funding of such a similar endeavor as you are running now? I am familiar with your work from years in the past and success that you have enjoyed.

Would you just comment on that for me, please?

DOCTOR CARRERA:: Yes.

The majority of our funding are from private, corporate and foundation sources. However, Governor Cuomo, through his Adolescent Pregnancy Prevention money gave us our first start and continues to support us in modest ways at the moment.

We have not been eligible for federal funding, because one part of our program has to do with the provision under medical supervision of contraceptives, condoms and other medically prescribed contraceptives, for young people who have gone against our injunction to delay having intercourse, who have not followed what we think is the best advice for them, and, that is, to delay having intercourse until some other point in their life, that having intercourse when you are 13, or 14, or 15 doesn't fit best then. It fits best later on in life.

But, in the real world, some young people are just going to have intercourse, and they are going to do it no matter

what we say as adults, and all we have to do is remember our own childhood or currently be a parent to recognize that all the things that we've said to young people don't automatically translate into their doing it. And, if they do get involved in intercourse behavior, someone has to be the adult and not turn their back on them, and not punish them because they are doing something that we've advised against.

So, what we do is, we provide them, when it's necessary, with contraception. However, we have found, and this is where I think there is a link to the HIV infection, that there are other things that have a contraceptive effect. Feeling good about yourself as a person, having a job and earning a dollar and having a bank account, performing well in school and having someone tell you that you have the capacity to achieve and to be competent has a contraceptive effect. Hope can be contraceptive in its impact, and I think that in the inner cities where HIV among adolescents is just on the bring of being reported, we need to develop more programs like this, because it's these kinds of things that will serve our purposes.

Yes, we must be explicit with information, and I agree with the Admiral in terms of his last comment to Masters, Johnson and Kolodny, we need more sexual literacy in this country. We need it for adults, and we need it for young people.

But, at the same time, we need to develop other avenues that will achieve our purposes. See, simply focusing on genital sexual activities as the way to solve a problem does a disservice to the possibilities of young people. Young people are smarter than that, and we really need to start to deal with them above the waist a little bit more.

COMMISSIONER PRIMM: What is, the actual cost, per person in your program to run such a program?

DOCTOR CARRERA:: Well, the Executive Director of the Children's Aid Society would probably quarrel with me, because he feels I'm a bit excessive in terms of what we spend. At the moment, we're spending between $1,500.00 to $2,000.00 per person, per year to run these programs.

Now that, of course, this figure must be balanced out against the $16.65 billion dollars that this country spent in 1985 to aid programs that began with the birth of a child to a teen, in the form of Medicaid, Public Assistance benefits and food stamps.

Our own attitude is that the government should be throwing money at us, but because we have, as one of seven dimensions of our program, contraception when it is needed, even though our philosophy is based on the premise that it's important

for young people to delay having intercourse, we have not been eligible for this support.

COMMISSIONER PRIMM: How many of those 217 go on to college?

DOCTOR CARRERA:: All right. We have a relationship with Hunter College in New York City, where I'm a Professor, where any young person in the program, or any of their parents who finish their high school diploma or get their GED, are automatically admitted to Hunter College, unconditionally, as another way to say there is hope for you, that there is something that you can achieve, and all it takes is making a deal with a college president. And, college presidents and college officers want to help. We need to be able to reach out to them to show them how they can help us.

So, right now we have ten young people and parents, who otherwise would not have been involved in a college education, who are currently at Hunter College. We have six more ready to go in the fall, and we have a full scholarship program, whereby they will be able to be supported in the event that they want to take advantage of this.

We consider this to be HIV prevention.

COMMISSIONER PRIMM: Thank you.

CHAIRMAN CRENSHAW: Doctor Gebbie?

COMMISSIONER GEBBIE: First, a quick question on the regulations that's restricting your access to funding. Is that a state regulation?

DOCTOR CARRERA:: Some of the federal guidelines having to do with the provision of funds for programs that offer on-the-premises contraceptives prevent us from getting into the channel of funding.

COMMISSIONER GEBBIE: Could you provide us later with this specifically, because I know in Oregon, through my public health programs, we do fund programs --

DOCTOR CARRERA: Absolutely.

COMMISSIONER GEBBIE: -- Using both state and federal dollars to provide those services, and I'd like to understand exactly how that restriction is affecting you.

DOCTOR CARRERA:: Absolutely.

COMMISSIONER GEBBIE: My other question is a broader one. Your presentation is consistent actually with several others we've heard, that says you are not going to attack this problem in any singular way, particularly with young people, that the holistic approach is a solid one. You described it very enthusiastically.

Can you identify what recommendation from this Commission, other than throw money at all these good programs, is there a policy recommendation or an attitudinal recommendation that we could make that you would find most important in both continuing to support your program and fostering the development of similar programs around the country?

DOCTOR CARRERA:: Well, first, I'm certainly an advocate for all of the means that we are currently utilizing and that we need to continue utilizing in the public education forum, that schools, at developmentally appropriate levels, must continue to provide young people with information that they must have as young citizens of our society about their own bodies, and how to protect themselves, and to understand about transmission.

I believe, secondly, that we need to influence the thinking of adults, mothers and fathers, who are the principal sexuality educators of young people, who are more important than I am. I mean, we have a parental component in our program. I'm going to be gone some day, but they will always be there with their children. We need to have more public education efforts to get them involved, to empower them to say what they must say to their youngsters.

And finally, I believe it's very important to support the notion that, by providing job opportunities and access for continuing education, including higher education, that providing medical care is a very, very important preventive mechanism, and that must be done through community-based organizations, not simply through schools and churches. There are many, many agencies and institutions around this country that have a day-in and day-out population of young people and adults that come within their doors and are under their roof.

What we need to do is to say to them, come up with creative ways of enhancing self-esteem and self-worth. Those opportunities will serve to prevent teen pregnancy, reduced sexually transmitted diseases and be HIV preventive.

COMMISSIONER GEBBIE: Thank you.

CHAIRMAN CRENSHAW: Doctor SerVaas?

COMMISSIONER SerVAAS: I don't know if this is a suggestion to you at Hunter College, but we have, at Indiana

University, a faculty member in psychiatry who thinks that we could get teenagers involved in competitive ballroom dancing, to get the little acne kinds. And, out in the middle West we have five kids on a basketball team, instead having all of these kids participating. And, her contribution in child psychiatry has been very substantial in the medical literature.

She would really like for me to present the idea that in getting these kids' self-image up, that you do a lot of competition, and there is an international competition in ballroom dancing, and I wasn't aware of it, but they compete all over the world.

DOCTOR CARRERA:: Right.

COMMISSIONER SerVAAS: And, it's just a recommendation. I should ask a question.

DOCTOR CARRERA:: Well, but, I think that the comment is certainly in the spirit of something that we do in our program, which is that we offer individual lifetime sports as compared to basketball, for example.

In Central Harlem, basketball is king and queen, and minority youngsters are capable of doing more than that, so we offer them individual lifetime sports, all sports that require self-discipline, mastery and impulse control. The kinds of things that we think we can generate within them in the arena of sports that can be transferrable to the time when they are alone with someone else, and they must exercise impulse control.

The more ways that you can get at it, the better we think it's going to be.

CHAIRMAN CRENSHAW: Admiral Watkins?

CHAIRMAN WATKINS:: I'm so in tune with you, Doctor Carrera. You know, I've been in New York several times. We're trying to get a partnership up there, and David Denkins and the others working with people from the Archdiocese --

DOCTOR CARRERA:: Yes, I'm aware of that.

CHAIRMAN WATKINS: -- to pick up on your holistic approach now, and set a New York City 2000 objective. You've got some serious problems there, that unless we get our arms around those youngsters and start moving this next generation, the nation is in serious trouble, and that's reflective of just New York City, but it's rampant everywhere where we have the large urban problems that we have, and you mentioned them.

This is why I mentioned earlier that, I think when we put sexual behavior change out of the content of a variety of intervention strategies, and just look at it as a separate line item, it becomes very controversial, and unnecessarily so, unless we put it in a larger context.

DOCTOR CARRERA: Yes.

CHAIRMAN WATKINS: This is all I was trying to do earlier, that I think it's important that we all talk in those terms.

We've been presented with some incredible and compelling testimony here in New York City, about the density of hopelessness as a function of AIDS, and it's direct.

DOCTOR CARRERA: That's right.

CHAIRMAN WATKINS: So, we know that. So, to leave that out of the system in trying to effect it in some mechanical way, seems to me to be missing the large body of compelling evidence that says you've got to do better than that.

DOCTOR CARRERA: Right. And, parents and communities are very much in tune with broad programs that include the genital sexual component, so long as along side are all the other aspects that make a young person who she or he is. Simply to focus on intercourse experiences and contraceptive practices, as the way to achieve our goal, is to make a major mistake. We in this field made that mistake a long time ago, and we're still paying the price.

CHAIRMAN WATKINS: I've seen in Atlanta, in Richard's Academy, that brings in about 600 disadvantaged kids every year that have fallen out of the mainstream and they bring them back, and they have about 100 percent success rate in putting them into productive work in society. It's an incredible experience to see what they do after the fact.

What you are doing is before the fact, which is cost effective from almost any point of view that we have, from a social point of view, from a dollars point of view.

So, I commend you for what you are doing, and I can tell you that I haven't given up on my efforts to get some inspiration going in New York, let's make New York City a role model for others --

DOCTOR CARRERA: Well, we'd like you to --

CHAIRMAN WATKINS: -- instead of the butt of all criticism --

DOCTOR CARRERA: -- visit next time you come.

CHAIRMAN WATKINS: -- in the nation for having the highest density of AIDS cases, maybe we can turn it around to say, yes, okay, but we'll have the fastest ramp to get to year 2000, something very special.

So, I commend you for your testimony and thank you for coming today.

DOCTOR CARRERA: I appreciate the opportunity, and please visit us next time you are in New York City.

CHAIRMAN WATKINS: All right.

DOCTOR CARRERA: I thank the panelists for indulging me in this fashion.

Thank you, Doctor Crenshaw.

CHAIRMAN CRENSHAW: No, don't go, because I'm not done with you yet.

You mentioned your seven point program, and you mentioned a few of the points. But, I'd really like you to run through, just very briefly, what the target areas are.

DOCTOR CARRERA: Well, we have an employment program which guarantees employment for every young person in the program, age range from 11 to 18. We pay the young people, 11, 12 and 13, in the form of stipends.

Right away, getting them on the track towards self-sufficiency, independence, we have a mandatory bank account policy.

CHAIRMAN CRENSHAW: Mandatory.

DOCTOR CARRERA: Yes, mandatory.

You know, in real life, when you get something you have to do something, and we have an academic program. One piece I mentioned, automatic college admission to Hunter College. We have a tutoring program and a homework help program. We have a medical and health program, served by adolescent specialists from neighboring hospitals. We have a counseling program, staffed by clinical psychologists and social workers, who deal with young people in terms of decision-making, as well as intrapsychic or characterological difficulties and family problems. We have the lifetime sports program. We have a self-expression program, communication arts, culinary arts, teaching young people how to

cook and how to express themselves through cooking, as well as silk screening, learning how to make tee shirts and sweat shirts, which is a business for young people. We have a family life and sex education program, which for many programs dominates the scene, but for us it is one of seven.

These things taken together make the whole picture for us, and the young people and parents come in and we serve them two or three times a week. Our ideal is for them to come in every day. We're open every day after school and all day Saturday and Sunday.

We recognize that the only way to make an impact in communities that are at risk, and I say that because I don't want to say youth at risk, it's communities that are risky. Young people live in communities where there are drug addicts, where there are dope sales, where there is no housing, where there is homeless, where there is unemployment, where people are ravaged by poverty. That produces a climate of risk, and our youngsters are growing up into that climate, and what can we expect.

And, unless we do something now, and hang in there for the duration, this next generation is not going to be health and productive. They are going to suffer the same way.

And, it really has been a shame for this country to allow this to go on without a public policy that seeks to make a dramatic and radical change.

CHAIRMAN CRENSHAW: Well, you know, I want to just add to the compliments you've received, that these are the kind of programs that so many people in the field of sex education and human sexuality have tried for, and been unable to achieve. You've done something that people said was impossible. You've gone to one of the toughest communities to reach, with all of the complications that are reflected in the AIDS epidemic, and you've gotten the job done, and you've done it cost effectively from everything that I can see.

And, incorporated in that, you give more than lip service to deferring sexual expression, but you are realistic enough to have the safety net there when it is needed, and I think that this is just terribly important. And, one of the key reasons that I invited you here is that, if someone can do it in as tough a community as you are contending with, we can do it all over the nation. It's just a matter of getting the models in place, and I hope you'll help us more with that.

DOCTOR CARRERA: I certainly will. I'm going to be sending more literature to the Commission.

CHAIRMAN CRENSHAW: Yes. I'm sure that you can, because you are one of the first witnesses that has told us what is possible, not what's impossible.

So, I want to thank you.

DOCTOR CARRERA: Thank you. I appreciate it.

CHAIRMAN CRENSHAW: And, please do stick with us as long as you can. Don't run off immediately, but, hopefully, we'll get enough time for questions before you have to leave.

CHAIRMAN CRENSHAW: Doctor Ehrhardt, we look forward to your testimony.

DOCTOR EHRHARDT: I'd also like to thank the Commission that I have the opportunity to testify today.

I am a clinician and researcher in the area of sex and gender, and for the last 25 years I've studied the determinants of psychosexual development in children, adolescents and adults.

I am also a Professor of Clinical Psychology in the Department of Psychiatry at the College of Physicians and Surgeons at Columbia University, and a research scientist in the New York State Psychiatric Institute.

And, most recently, I'm the principal investigator and director of a newly established HIV Center for Clinical and Behavioral Studies, supported by an award from NIMH and NIDA.

I'd just briefly like to say a few words about that. Approximately a year and a half ago, my colleagues and I developed a proposal for a research center which subsequently was funded and then became the HIV Center for Clinical and Behavioral Studies. This center is directed from the New York State Psychiatric Institute and includes now more than 100 researchers and clinicians in Psychiatry at the Columbia University School of Public Health, Presbyterian Hospital, St. Luke's, Roosevelt and Harlem Hospital.

Our choice of research studies reflects investigations which we thought were urgently needed to give us answers concerning the prevention and progression of AIDS. We are, therefore, currently conducting research on perinatal AIDS, and on the progression of HIV infection in IV-drug using men and women, and gay and bisexual men.

We also have launched a major prevention effort focused on different groups of adolescents.

The unique feature of the HIV Center is its interdisciplinary collaboration. We have attempted to bring in the expertise of many researchers to focus on different aspects of the problem in order to come more rapidly to scientific breakthroughs and methodological developments.

The HIV Center, specifically includes three adolescent prevention projects. One is an adolescent prevention model program for high schools, and we work with all 14 Manhattan high schools and two suburban schools. We are developing a teacher-delivered cognitive behavioral AIDS prevention program, which will be assessed for its effectiveness.

The second adolescent study is an AIDS prevention program for runaway and gay youth, and, of course, I couldn't agree more with what Doctor Carrera just said, it's very clear that we have to take a much more global approach also.

And, the third one is an AIDS prevention project for adolescent sex offenders. We have, at out institution, a Sexual Behavior clinic which specifically works with sex offenders mainly young black males, and we have added on a prevention project for HIV infection.

Now, my testimony will focus in particular on sexual behavior in the context of the risk of HIV infection and of modifications of risk behavior. As you have heard in the previous panel, and also from my two colleagues just now, clearly our knowledge base on sexual behavior is unfortunately very fragmentary and not complete.

We know that it is one of the behaviors that is almost universally expressed throughout the life cycle and by almost all people. However, children vary in the expression of their sexuality from adolescents, and adolescents vary from adults at different age points, and in different life situations.

Furthermore, because cultural norms play an enormous role in modifying the expression of sexuality, there are different patterns for different groups of people.

Gaps of knowledge leads to stereotyping and myths which obstruct our efforts to design effective prevention strategies in combatting this deadly disease. It is, therefore, of high priority to fill our knowledge gaps by acquiring new data, so that we don't have to fall back again and again on data that is outdated or based on too limited samples of people.

Now, why are adolescents a priority? As we heard so far, only relatively few adolescents, thank God, have been reported to have developed AIDS. However, about 1/5 of all people with AIDS are in their 20s, and it is likely that many of

them became infected during the adolescent years. We don't have a good data base, how many adolescents already are HIV infected without symptoms of AIDS.

You have heard from Doctor Baldwin, and I will not repeat that, and Doctor Carrera mentioned also, that by the time adolescents graduate from high school, or are 17 and 18 year olds, about 50 percent, as a conservative estimate, have experienced sexual intercourse. There are other data, such as local data in New York, which suggests that on young women in a detention center in New York City, had an average age of first sexual intercourse at 12. Most of the young women had sexual contact with multiple partners, and knew little about their sexual partner's sexual or drug-related behavior.

This is just to highlight that we need to be sensitive to different groups, and that when we talk about norms, we only talk about averages which, obviously, vary.

The data which we have at this point on sexual behavior give us only bare-bone information on which we must build effective prevention strategies to modify risk behavior.

Therefore, while rapidly designing and evaluating model programs of prevention, we must simultaneously enlarge our data base to answer questions regarding the sexual practices of adolescents, the sexual milestones among different groups of adolescents, because they will be critical for the design of prevention strategies.

Most of all, we need to increase our repertoire of knowledge on cultural norms and behavior patterns among different groups of the population.

Most studies have either lumped all adolescents together or focused on middle and late adolescence. I would suggest that we need to specifically focus on early adolescence, 12 to 14 years of age. We have to know the determinants and patterns of this age group before establishing a pattern of risk practices for HIV infection.

I'd like to say a little bit about children, since we mainly have talked about adolescents. I do think it is very important that we need to know more about children's sexual beliefs, attitudes and behavior in order to do what has been called for, namely, a curriculum from kindergarten through elementary school.

That certainly has been one of the taboos, to talk to children about sexuality, although clinicians and researchers, like myself, are very well aware that you can talk to children at any age as long as you do it in an age-appropriate and sensitive

way. And, children are not asexual, as sometimes it is suggested in the literature. Indeed, children rehearse and play act any kind of important behavior, any kind of role rehearsal, including sexual behavior.

Now, the goals, what are the goals, and we have given this a lot of thought in terms of programs to change sexual risk behavior for adolescents. Obviously, with all the consideration of having a holistic approach, ultimately what we want to achieve is to delay sexual intercourse, reduce the number of casual partners, increase communication, social skills and assertiveness to implement behavior change.

So far, the attempts which have been made, in terms of behaviorally-oriented AIDS prevention programs, have not been evaluated, but there are some important lessons which we can learn from sex education programs, such as Doctor Carerra's.

At this point in this country, sex education in schools has gained a broad public support and is part of most curricula. Hardly any sex education is given, is delivered in elementary school, and, unfortunately, most sex education programs are not evaluated.

Because this country still has a serious teenage pregnancy problem, and adolescents are reported to have high rates of STDs, as we heard, there is always a kind of sense of despair that nothing works and everything is unsuccessful.

When you look more carefully what has to be done, then the picture is really by no means as bleak. There are some enlightening model programs, such as we heard, which certainly can give us very important lessons for what we should be doing in terms of AIDS education. And, I'd like just to list that for you. These are also the lessons we have learned, and at the same time, my suggestions and recommendations.

1. AIDS prevention programs need to be developed within many different settings, as part of an integrated health education curriculum in school, and within school-based clinics, and as a comprehensive community effort involving community centers, churches and family programs.

2. AIDS prevention programs need to be behaviorally based, rather than just knowledge based. They need to include social skill training and role rehearsal, and be comprehensive in increasing life options for adolescents, as we just discussed.

3. We need to use innovative educational methods that have been shown to reach teens, such as hot lines, educational print, audio and video material.

4. The mass media need to be included in a global effort to increase knowledge, change attitudes and to make behavioral change possible and probable.

5. Most of all, we need to develop model programs which include evaluation as an integral part. We need to assess which components affect positive behavioral change and which do not.

6. We need to build on the experience of existing programs and integrate them into new programs.

7. We need to set up mechanisms for rapid dissemination of information about effective prevention programs.

8. Collaborative efforts should be encouraged and fostered through specific funding initiatives in order to maximize different expertise for the establishment of the effective model programs.

9. There has been a national discussion on the advisability of early AIDS education in elementary schools. Age-appropriate curricula for children should be developed based on sound child developmental principles. The curriculum should be integrated into a life course to teach children about social roles, responsibilities, communication skills between boys and girls, and information on sexuality and reproduction.

10. And, I think this is very important and we often don't include that in our recommendations, we need to take care not to impair healthy sexual development in children and adolescents by imparting negative and fear-arousing messages without teaching alternatives that are compatible with sexual pleasure and positive affectional relationships.

Now, let me just make a few comments about the barriers of implementing a program like that and then I will close.

1. Sexual behavior is strongly influenced by cultural norms. Adolescent education is determined by the opinions of authorities, parents, schools, the state, the federal government and churches. Conflicting opinions on what should be taught are based on attitudes and norms, rather than on empirical data. We are now dealing with a deadly disease. We have to agree that prevention of HIV infection is a priority for all children and adolescents in this country. Delaying effective AIDS education for children and adolescents might cost them their lives.

2. There are prevailing myths and stereotypes which have been disproved by empirical evidence. Those myths need to be corrected. Specifically, we need to lay to rest the shibboleths that education about sexuality accelerates the age of

first sexual intercourse. We have some good opposing evidence, namely, that programs can delay sexual intercourse.

3. Another myth is that one cannot communicate with children and adolescents about sexual behavior without upsetting them. Teachers and health educators need to be trained in talking to children and adolescents about the subject.

4. We lack important data on the sexual behavior patterns, which we rapidly need to correct.

5. We need new alliances. Currently, experts of different disciplines do not sufficiently collaborate. Traditionally, prevention programs are developed by service providers, educators and prevention researchers, and sexual behavior studies have been conducted separately by sex researchers. We need to find mechanisms to cement these efforts. In addition, we need to bring in experts on the development of educational material. We need to work closely with community experts, anthropologists and service providers who have the grass-root experience to implement prevention programs, and all programs must be evaluated.

6. Traditionally, grants have given researchers not enough time in which to develop comprehensive programs and evaluate them. Therefore, new creative, collaborative funding initiatives need to be developed to foster interdisciplinary and collaborative efforts. Examples are centers, program projects, mechanisms to fund demonstration projects with evaluations, and conferences with rapid publication of conference reports.

Thank you very much.

CHAIRMAN CRENSHAW: Thank you, Doctor Ehrhardt.

CHAIRMAN CRENSHAW: Next, we have Ms. Tatum, who is a teacher on the front lines, and will share with you her point of view.

MS. TATUM: Thank you, Theresa.

Thank you very much for inviting me here today. I am here because I've spent the majority of my teaching career with adolescents, parents of adolescents and children, and with helping professionals as a teacher.

For 14 years, I've taught the Family Life Sex Education Program at George Mason Junior/Senior High School in Falls Church, Virginia.

For the last several years, I've taught for the University of Virginia a graduate course in Family Life Sexuality

for Teachers. I had the privilege of working with school systems around the country to implement programs and train their teachers. I worked with Roman Catholic, Baptist, Presbyterian, Hebrew and Episcopalian congregations and schools.

My perspective on AIDS education also comes from my experience with applied learning theory. I have served on the AIDS Policy Committee of the American Association of Sex Educators, Counselors and Therapists, and speak, in part, from that policy today. I am currently the Director of the Family Life Unit, Center for Applied Research and Development at George Mason University.

AIDS education -- the Admiral gave my speech earlier, and I appreciate it very much, and hearing from Wendy, and Michael, and Doctor Ehrhardt as well this morning, I'm very pleased to know that there is a body of knowledge and an attitude that has become common among us, that it is no longer one or two people speaking out and the rest sort of sitting back and disagreeing that, perhaps, that hasn't been well enough researched, or we really don't know what we are talking about, that over the 15, 16 years that I've been in this field, that we have arrived at some cohesive kinds of ideas about what needs to be done.

Michael's statement about the human sexuality or the family life plan and family planning units being a part of a comprehensive program can also be true in schools and communities. When you teach a comprehensive family life sex education course in a school, it is one course among the 20 to 30 courses that a young person might take in a high school, but before that time, kindergarten through six, we must also have an age-appropriate development of understanding our bodies, where our bodies are going, what we do with our bodies, our minds and our spiritus. And, the fact that public education and most institutions in our communities have left out those discussions over the years makes a very loud statement.

Most of us went to school when in all biology text books and health text books, all the diagrams had human beings cut off at the urinary bladder, and the time has come where that is not the focus of family life or sex education. Certainly, that needs to be a realistic part of what we are talking about.

I offer as some evidence the ways in which we have done sexually transmitted disease education. It has been required or mandated in virtually every state in the country for many years. The American Social Health Association was one of our first sex-related national organizations in this country, and 2.5 million young people contracting a sexually transmitted disease last year tells me we are not very effective. And, I know how it's taught, because I'm there, and it's taught by the health and Physical

Education teachers who don't like classroom teaching, don't like talking about STDs, aren't trained for it, or for classroom teaching, and they talk about it without ever mentioning sexual decision-making, or sexual behavior. It's as if the great gonorrhea sore in the sky soars around and goes "whoop" and gives it to somebody. It is never talked about as if that infection passes sexually from one person to the next.

And, God forbid that we should talk about any kind of contraceptive prevention, because as soon as we talk seriously about sexuality in this country, a committee gets organized and opposes it. Everything else goes. The pornographic nature of our television, our media, our film, our magazine industry, our nice jokes even at the best of cocktail parties goes unchallenged. What always gets challenged is those few people who are very fearful for their very own reasons, and I'm not putting them down in any way, very fearful and angry for their own reasons about sexually-related issues, who organize and oppose this institution that is so important in the lives of children, the public schools that we force them to attend by law, and they are fearful that if we begin talking about those kinds of decision-making possibilities that their children will become prematurely sexually active.

First of all, kids will experiment. There is no question in the minds of any developmental person I've ever read with any respect at all, that we will expect that adolescent kids will experiment with various aspects of life. We need to give them a platform of knowledge, starting in kindergarten, of knowledge, attitudes and skills, and assertiveness skills, so that when the catalyst comes, and the catalyst can come in the form of a very attractive young man or a very attractive young woman in the back seat of a van at midnight, when there's been a little alcohol involved, and when that catalyst comes, if there is a platform there of knowledge and skills, et cetera, perhaps, the catalyst will not be in charge.

But, if there is no platform of knowledge, attitudes and values recognized by that young person, the catalyst is in charge. They are standing on the ground, and they have no base upon which to make those decisions.

Secondly, I want to say, telling is the least effective thing we do to adolescents, and that's something that the American parent mentality has great difficulty with. I do, because I have children myself. I want to tell them what to do. I want to tell them they'll get an incurable disease. I want to tell them they'll get pregnant, and I do, and as a parent I should be doing that because it transmits my values.

But, in the peer setting where the norms are set, there needs to be a respect for the integrity of young people. That's

the heart of Michael Carrera's program, which I've watched with great interest. The respect for the integrity of those young people that says, we're going to give you this information, but we're going to work with you to talk it through so you can share with each other in this peer setting what these norms are, perhaps, what they should be to protect your own health. That, I call freedom to learn.

The cultural messages, of course, are very confusing, and I'm not even going to say anymore about that, because I'm sure you have heard a great deal. We occasionally get a television show that says something positive, and the kids are all quick to assure me that there is some rock music that doesn't talk about sex and drugs, and they are also quick to assure me that there are two or three television programs that have good, strong, positive value messages, and I think we know what the rest of it does.

Comprehensive family life sex education in this country, in its public and private schools and religious communities, does not exist. There is absolutely a dearth of good programs, of even good model programs. Local communities need to develop their own programs, but we need national leadership.

I have previously been opposed to state mandates for family life education programs, knowing that bureaucracies often do not do the kind of job I would like to see done, but I have reversed myself because there are so many people out there in Allegheny County, Virginia, who need the support of leadership like Doctor Koop, and more specific leadership at the federal and state levels that say, we want you to have these programs. They are very important programs. There is a lot of scholarship and there is a lot of research, and there is a lot of academic reason to do these things, just from the standpoint of making life better for young people.

We need that. It needs to be age-appropriate, and, again, the weakest link probably will be and is in the training of teachers and people who work with young people. I offer that. Thank you very much.

CHAIRMAN CRENSHAW: Thank you.

CHAIRMAN CRENSHAW: Before Doctor Fishbein begins, I'd like to offer a little introduction, because you might ask, once you hear what he's going to talk about, why he's on this panel.

He is not a sex educator, nor a sex therapist, but I think that with the needs that we have in modifying behaviors successfully and effectively, we need to borrow from other disciplines, and his expertise is in behavior modification,

persuasion, influencing behavior in a positive and a productive way, and he is also not an expert in AIDS, although, correct me if I'm wrong.

And so, I am hoping, and we had discussed lending the skills that have been well developed in this discipline to all of the objectives that we are expressing throughout this day and many other portions of the Commission, and we would very much like to hear what you have to say.

DOCTOR FISHBEIN: Thank you very much, Doctor Crenshaw.

It's true, that am not an AIDS researcher, nor an expert in adolescents or in sex research. I am a Professor of Psychology and a Research Professor in the Institute of Communications Research, at the University of Illinois at Champaign Urbana.

I am best considered a an applied behavioral psychologist concerned with studying the relations among beliefs, attitudes, intentions and behavior. My testimony will focus on some general principles of behavior and behavior change.

I would, however, like to begin with an observation that's been made before. We know very little about the frequency with which different segments of our population engage in high or low-risk sexual or drug-related behaviors.

Information of this type is absolutely crucial. Admiral Watkins asked, what we would to do with this information? Why are we asking to get this information?

This type of information is crucial because we need to know what people are doing in order to know which behaviors to change and which to reinforce. It makes little sense to try to change a behavior that's not being practiced, and if we don't know how many people are engaged in a certain activity we may be wasting our money trying to reduce the number of people who are engaged in that activity. This is particularly true when we try to change behavior in certain communities, in certain areas.

We also need to know when, that is, at what age, people initiate or stop certain behaviors, in order to know when an intervention is most likely to change or maintain behavior.

One of the things that we learned from the research on smoking was that there is an appropriate time to intervene to reduce the likelihood that young children will start smoking. If you start too late, if the education comes after a certain age, it will have little or no impact on behavior. This is also true if you start too early, it has very little impact. So, researchers were able to determine that there is a time frame

where intervention is important. If we don't know when these transition periods occur, we'll never be able to discover these time frames.

So, my first recommendation is that we have to fund research to determine the sexual and drug-use behaviors of the U.S. population. And, while I believe that major nationwide surveys on sexual behavior and drug use are necessary, I'm equally concerned that funding be provided for a number of small, relatively quick surveys in given groups or segments of the population.

These surveys should identify the behaviors to be changed or reinforced in that group, and they should be conducted prior to developing an educational program or other form of intervention for that group.

Now, obviously, to develop successful educational programs, or other types of interventions for maintaining or changing behavior, one has to understand the determinants of that behavior.

In my written testimony, I provided one model of behavior change. There are several models of behavior change that are available. Time is short, and in five minutes I'm not going to be able to describe the theory of behavior that's taken me 25 years to develop, nor will I be able to describe alternative theories that my colleagues have developed. But I would like to point out that there is now some general agreement that, to a large extent, a person's performance or non-performance of any behavior is first and foremost related to, or is a function of, their intentions to engage in that particular behavior; and that intention is a function of or related to two basic kinds of factors.

On the one hand, intentions are related to a person's attitude towards performing the behavior, that is, whether they think performing the behavior is a good or bad thing to do. And, on the other hand, the intentions is related to the person's perception of the social norms, a concept you've heard much about today. Social norms reflect what a person perceives important and what others think he or she should do. Should they or should they not perform this behavior?

These two components take on different weight for different behaviors and in different populations. One of the reasons this is important, is that, if it turns out that intention to engage in some act, to use a condom for example, is more under attitudinal than normative control, this would suggest that peer pressure will not be an effective way to bring about change. On the other hand, if this behavior is under normative control, peer pressure may be very effective.

The importance of attitudinal and normative considerations varies from one behavior to another, and even more importantly varies from one population or segment of the population to another. So, for males, the intention to engage in premarital sexual intercourse may be largely under normative control, while for females it may be largely under attitudinal control. One implication of this is that if we are to develop effective interventions, we have to know whether attitudes or norms are playing the most important role in determining the behavior in question.

In addition, most theories now agree that an attitude towards some behavior is a function of a person's beliefs about performing that behavior.

This is also important in terms of developing educational programs or interventions. One of the things it clearly points out is that one's feelings of favorableness or unfavorableness toward engaging in some behavior is not a function of any one belief. When we look at attempts at behavior change that have taken place in the past, we find that in many cases the information provided focused on a single health issue. so you don't smoke because it is bad for your health, or it's For example, many messages argued that one should not smoke because it is bad for or dangerous to your health. That message was very quickly learned by many kids, yet they continue to smoke. The reason they continue to smoke is because there are lots of other factors that are related to smoking. They have other beliefs about the disadvantages and disadvantages of smoking. And those who continue smoking, believe the advantages outweigh the disadvantages.

What I'm worried about is now is that we're talking about increasing condom use, and we're developing the same types of single focus messages. We're stressing the use of condoms because it's a prevention against AIDS, but that's not the only belief kids not the only belief that adults have about using a condom. If one has been involved in a long-term relationship, and all of a sudden he or she tries I try to introduce a condom, what that person may worry about is, whether will using a condom or asking one's partner to use a condom will get their partner to start thinking they've been unfaithful or that they no longer trust them. And, those kinds of broad factors or other beliefs about the consequences of performing a particular behavior have to be taken into account.

We can't simply focus on the one belief that using a condom will prevent AIDS. This point is related to some of the comments that were made earlier. We've got to look at things in the context in which they occur.

One other point that I would like to make, is also an implication of these models, and of the notion that behavior is a function of intentions. Although often not recognized, different intentions underlie the invitation, maintenance and cessation of a given action. To illustrate this, let me again use smoking because I'm more familiar with that domain than with AIDS or adolescent behavior. With respect to smoking there was a great deal of concern because the factors that lead to the initiation of smoking are different than those that lead to smoking maintenance, and these in turn, are different from those that lead to the cessation of smoking. Rather than being a problem however, this points out that these are different interventions.

In the same way, the factors underlying the initiation of sexual behavior, the maintenance of sexual behavior and those that will get people to stop certain kinds of sexual practices are likely to be very different, and hence will require different types of interventions. And, and an intervention that's good at preventing the initiation or delaying the initiation of sexual behavior may be totally ineffective as a means of reducing on-going sexual behavior.

In order to develop effective interventions, we have to understand what people's beliefs about engaging in a particular behavior are. We have to change specific intentions, not intentions in some vague, general sense. I was delighted to hear, people talking about an intention to use a condom.

If I increase people's intentions to engage in safe sex, there is absolutely no reason to assume that that's going to be translated into using a condom regularly or reducing the number of partners or that it will effect any given action. All too often our programs are directed at nice, broad global kinds of policy statements. We want zero population growth, or we want safe sex, or we want, abstinence. But, these programs are not going to be effective unless you tell the audience what specific behaviors to perform and give them some training in how to carry out those behaviors.

So, I think that we not only need research to find out what sexual and drug behaviors are being performed by both adolescents and adults, but also, to find out what they believe about engaging in these behaviors. What do they see as the advantages and disadvantages of performing these behaviors? Who are the individuals that they perceive as supporting their engaging in these behaviors? Who do they see as disapproving? Because, without that information, I don't think we can develop effective behavior change programs.

I suppose what I'm trying to say, and I may not be saying it as well as I would like to, is that many educational campaigns and interventions have been unsuccessful because they

haven't focused upon appropriate intentions, and/or because they haven't been based on scientific information, but have been developed on the basis of people's intuitions and assumptions about why people behave the way they do. And, more often than not, our experience has shown us that these intuitions and assumptions about human behavior are incorrect. Someone decides to use peer pressure, but the behavior is attitudinally controlled. In another case an expensive educational program is developed to give people all kinds of information, and it turns out the reason people engage in the behavior is because their close friends and others that they respect and admire think they should perform that behavior. And so, the interventions turn out to be costly and not too effective.

They also fail because we often fail to take into account the fact that there are enormous cultural differences. You cannot assume that the beliefs of a young Hispanic male about using a contraceptive are similar to or even close to the beliefs of a white Anglo Saxon male of the same age. The beliefs that underlie a given behavior are going to vary from one cultural group to another, and within cultural groups. The brief underlying Mexican Hispanics use of condoms maybe are very different than those of Puerto Rican Hispanics. We have to find out what people believe to develop effective intervention programs.

So, my second recommendation is that we have to fund research identify at the cognitive determinants of behavior, to give us the information we need to start developing effective programs.

Since time is short and I don't want to take too much time, let me just quickly make two other recommendations. I think it is essential, and other people have said this, that -- no, I guess this one people haven't said -- that funding has to be made available for developing effective messages. Many people have talked about the need for research to identify the factors influencing a given behavior, but once this information has been obtained there is a lot of work required to convert this information into an effective educational program; there is a lot of work involved in developing good messages.

For example, advertisers don't sit down, I make an ad and put it on the air. There is an enormous amount of copy testing that's done. There is an enormous amount of pre-testing to make sure that the ad is understandable. Ads are written in different languages for different segments of the population; the content of a message may stay the same, but advertisers recognize the necessity of talking to people in their own vernacular, in order for the message to come across.

Thus money is needed, not just to do the research, but to develop intervention programs; to do copy testing, to make sure that messages are written in a vernacular that is understandable to the target audience. My third recommendation, then, is that funding should be made available for developing effective messages.

Since my fourth recommendation has been made by others, I won't dwell on it for any period of time, but I too want to recommend that funding made available for evaluation research. It's silly to have an intervention program if you don't evaluate is effective. Particularly when one is dealing with a complex program, it is important to have some way of determining which aspects or elements of that program have been successful and which have been unsuccessful.

Funding is not only needed to conduct evaluation research, but to develop new procedures for evaluation. We need procedures for differentially evaluating different types of intervention.

My final point is, both a closing comment and a final recommendation. I think there's now a fairly general consensus that at least at the present time behavior change is the only way we can prevent or reduce the spread of the HIV epidemic. Unfortunately the phrase, and I quote, "at least at the present time," implies that behavior change is merely a stop gap measure until a vaccine or cure becomes available. Such a view is short-sighted and dangerous. The availability of hepatitis B vaccine has not eliminated hepatitis, nor has the availability of contraceptive technology eliminated unwanted pregnancies.

Clearly, even if a vaccine becomes available, behavioral issues will still be important. It will continue to be necessary to maintain low risk and reduce high risk sexual and drug use behaviors. In addition, there are many other behavioral questions that should be addressed. These range from concerns about getting people to care for AIDS patients, including the problem of assuring we have enough doctors, nurses and other health care professionals, to concerns about changing behaviors of those already inflicted with AIDS, to concerns about changing or preventing discriminatory and prejudicial behaviors with respect to those afflicted with AIDS.

Thus, my final recommendation is to provide at least as much funding for behavioral AIDS research as for biomedical AIDS research. The social and behavioral sciences can make a major contribution to the fight against AIDS, but like everything else this will cost money. Given the central role of behavior in the AIDS epidemic, it's essential that the social and behavioral sciences receive the same level of funding as that given biomedical research. Thank you.

CHAIRMAN CRENSHAW: Thank you so much, Doctor Fishbein. I deeply wish we had a full day to put on a further panel to really go into the fine points of the message and the different complexities of getting that same message across to so many different subcultures and different ages in our society.

CHAIRMAN CRENSHAW: I'd like to begin the questioning by asking you a hypothetical question to see if you can give some examples of how this could be accomplished.

We have one group who fears that if you recommend condoms that no one will be exclusive and it's giving permission. And we have another group that fears that if you comment on the fallibility of condoms and the full scope of the information about the fact that they're not entirely secure protection, that condoms will be thrown out the window and not used.

It's my perception that in spite of these opposite polarities, the majority that I've talked to in either camp have the same desire. They want for our adolescents to defer sexual activity as long as possible. Not just for AIDS reasons, but to get them through school and to help them with a lot of other things. But most of them, even on the far right, that I have spoken with, if the kids are not going to follow our very best advice, want them to have a safety net.

So, can you help me develop some common ground here by pointing out how both messages can be given in perspective without being lip service to either one of them?

DOCTOR FISHBEIN: Well, I think you heard the answer to that earlier this morning in Dr. Carrera's description of the program in New York.

CHAIRMAN CRENSHAW: Recap it if you would.

DOCTOR FISHBEIN: You have to put things into context. You can't turn back the biological clock. If children are already engaging in sexual intercourse, and particularly if they're doing it on a regular basis with one partner or even multiple partners, you're not going easily to stop that behavior. It would be very difficult and probably not very cost effective to try to stop them from having sex.

So, for that group, it's very important then to make sure that they're using whatever protection we can provide them. In that group you can intervene and try to convince them that a monogamous relationship is appropriate, that it's better not to have more than a single partner.

Goals have to be different depending on the behaviors that are occurring in the population under consideration. If you go into a classroom where you know that 99 percent of the kids in that class are sexually inexperienced, you can present information designed to prevent or delay the onset of engaging in sexual behavior. You can develop interventions to prepare the students for the kinds of platforms that we heard about earlier.

On the other hand, if you walk into that classroom and 75 percent of those kids are already sexually experienced you'd be wasting your time and you're trying to tell them that virginity is admirable and not that engaging in sex should be their goal. Moreover, you're likely to alienate them and they may well to tell everybody else that your program is just a lot of silly nonsense.

So, it's not so much a question of funding common grounds as it is a matter of recognizing that the appropriate intervention will depend on the behaviors that are being performed. There are things you can do with sexually inexperienced children, and there are things you can do with sexually experienced adolescents, children and adults. I think we have to design our programs to deal with certain reality as opposed to trying to pretend that nobody's doing behaviors do not occur among young children and adolescents.

CHAIRMAN CRENSHAW: Thank you.

Doctor Primm, would you like to defer?

COMMISSIONER PRIMM: Yes, just come back to me.

CHAIRMAN CRENSHAW: Doctor Gebbie?

COMMISSIONER GEBBIE: My first question is to Doctor Baldwin. I'm sorry I didn't hear your presentation, but this is actually a follow-up on something we heard from some witnesses yesterday, that the adolescent population is a very critical one. You've provided us with some additional data about just why that is so.

The gist of some of their comments was that we are hampered in pursuing that because there is no central point within the federal research or support agencies to which those interested in adolescents can come to get support and an integrated approach to what they're doing with adolescents. Do you have any comments or view on that?

DOCTOR BALDWIN: Well, there's certainly not a central point in terms of all programs that would deal with the many, many facets of adolescent behavior, but in terms of research, there are really only one or two places that are

supporting research and I think AIDS has impelled us to working together a little more closely than we had in the past.

There is a great deal of enthusiasm for comprehensive programs like Doctor Carrera has described. I don't know what his particular hurdle was regarding service program funding, but there is always a tension between whether you should have specific programs for pregnancy prevention, HIV, STDs, or drug use or whether it's possible to organize all of those programs in one.

I am not sure that can be resolved. I think perhaps the more important message is that there has to be national leadership about the importance of different programs working together. It is possible for different federal programs to work very well together if they are all working towards the same goal and if there is a sense of real commitment behind the problems that they're working on.

So, I am not sure that a bureaucratic reorganization is actually necessary or is even the best way to achieve what I suspect people want to achieve. I think there are other ways to do it.

COMMISSIONER GEBBIE: Well, let me push just a little harder on that. Say I'm somebody in a community that's work has been working with kids for awhile and I want to follow up on some of the ideas that we've heard here today -- say Ms. Tatum is galvanized to do even more. She's already done a great deal, but to get hooked up with five other local organizations and really work with the adolescents in her town involving multiple organizations and she wants to build into that a good, solid, evaluative component of the impact of what she's doing on the physical and emotional health of the adolescents in her town.

Where would she start calling to find out what the sources of support -- if she wanted to find out the effect on the hearts, she'd call the National Institute of Heart and Lung. If she wanted to know about the impact on the people over 65, she'd call the Institute on Aging. Where would she call if her interest is adolescents?

DOCTOR BALDWIN: Mary Lee is going to do that. I certainly hope she's going to call me.

COMMISSIONER GEBBIE: Is that appropriate or is that just because she knows you?

DOCTOR BALDWIN: It is appropriate. Research programs are funded through the National Institutes of Health. Many of the service programs are funded through other agencies. The problems in evaluation research, I think, are more a problem

that sufficient funding is frequently not available. The service provider who is on the line and who has to decide whether that last dollar is going to go into more service or into the evaluation, will frequently put time into service and I can understand that.

My institute, in fact, right now is taking steps to see how we can bring what we have done in the research arena into evaluation, which has not been a high priority in the past. We think that we can do it now. One of the ways we're trying to do it is by working with other agencies. So, if she has a program that relates to drug abuse and to fertility behavior, she really will have to talk to two agencies at least, maybe three.

I don't have an administrative solution to that other than trying to involve multiple agencies.

COMMISSIONER GEBBIE: You do confirm what we've heard, that it's going to take some juggling and multiple people?

DOCTOR BALDWIN: Yes.

COMMISSIONER GEBBIE: My other question is to Ms. Tatum, although anyone else can join in answering it.

It's really a little tempting after we've heard what we've heard this morning to think that one of the suggestions we should just make is to say "Let's get into this wonderful, holistic parade." I'm not sure from what I heard you say that you would view that as a sufficient recommendation from us to really move things forward. You've worked in this field a long time.

I want to stay from the just pour money into it side. In the policy or public attitude side, can you identify what one or two things this Commission could say that would really make things better for you and people like you trying to accomplish things for the young people in this country?

If you were writing our thing for us, what would you want us to say?

MS. TATUM: I would very much want to say that state boards of education and local boards of education, in light of the mandates for AIDS education that have gone out all over the country, a video tape and a two page printout with what PE teachers should say to their kids, that the recommendation from you be that same communication channel be used, the state boards of education to the local boards and the local school systems, but that it be for a comprehensive institution of programs from kindergarten through 12.

I think in order to do that, the complexity would center around the development of resources, not of curriculum. The American way is to do it locally. Not of curriculum but of resources for that curriculum and, most importantly, for teacher training. Some models that could then go in a tree-like way down to the regional and local levels.

There are some people doing some few things and that's all there is. The state of Oregon, for instance, has a very comprehensive state level AIDS education program, very well done and very comprehensive. [And I looked at it and I wish that every --]

COMMISSIONER GEBBIE: That was not a set up answer. That's where I'm from.

MS. TATUM: No, it wasn't. I just happened to be in San Francisco last week and the author of the curriculum was there and so I looked at it. I thought you would identify with that, at least.

But my question would still be, who's going to teach that curriculum and how is it going to be taught, very much what Doctor Fishbein is saying to us. That would be the most important thing this Commission could do.

CHAIRMAN CRENSHAW: Doctor Primm?

COMMISSIONER GEBBIE: I had another question, but I won't pose it to them.

CHAIRMAN CRENSHAW: We're a little short on time, so we'll do our best. Doctor Primm?

COMMISSIONER PRIMM: I had a question for Doctor Fishbein, Ms. Tatum and, of course, Doctor Ehrhardt.

It has been pretty much assumed throughout the United States that wherever we have gone that the behavior of addicts is very difficult to change. If you get them to change their drug using behavior, then you certainly have a great deal of difficulty getting them to change their sexual behavior and using condoms.

I would like to ask any of you, what do you suggest would be a good way to go about trying to change behavior among the drug addicted, intravenous drug abusing population. That's number one.

The other question is, there seems to have been some conformance with Doctor Carrera's or some endorsement of the plan that he has used that has been effective, that seemed to be

effective of course, in the Harlem community. Would you endorse such a plan to happen in other cities to us because it seems to me that it has worked rather well?

For you, Doctor Ehrhardt, my question was, you had noted in your presentation that you had a relationship with some of the community based agencies, specifically the Minority AIDS Task Force in Harlem, the Hispanic AIDS Task Force, I would imagine, the Manhattan AIDS Task Force and the Gay Mens Health Crisis. Somehow after the response to the other questions, if you could enumerate exactly, specifically what is the relationship with those organizations in that community which you serve?

DOCTOR EHRHARDT: Do you want me to start with that?

COMMISSIONER PRIMM: Well, Doctor Fishbein.

DOCTOR EHRHARDT: Okay.

DOCTOR FISHBEIN: Okay. The first question you asked was about drugs and what could be done about drug users. I think it's safe to say that it depends upon the behavior you want to change. This is one of the points I was trying to make, that every behavior is different. If you're trying to get people to stop using drugs, that's different than if you're trying to get them to clean their works, to use bleach.

Many addicts have a considerable amount of control over their behavior. They don't shoot up work all the time. For example, there are many IV drug users who hold jobs and they don't shoot up at work. So, they can time the times that they do it. They control certain aspects of their behavior. We've seen enormous reductions in the amount of needle sharing that's going on, which is one way that AIDS is changing drug using behaviors.

So, part of what can be done depends upon the behavior that you're willing to settle for. If you're only going to interventions designed to get people to stop using drugs, you're going to be a lot less successful than if you design an intervention that's directed reducing the spread of AIDS, trying to get IV drug users to not share needles, and to clean the needles that they're using. So, I think that targeting the behaviors is part of it. I think the other, problem is that we don't know why people are using drugs. There are different reasons. One of the beliefs --

COMMISSIONER PRIMM: Maybe because they're good.

DOCTOR FISHBEIN: Well, that's a very good possibility.

COMMISSIONER PRIMM: The thing is that you based your behavior change on changing the belief system and with the constant reinforcement that you get from opiates, for example, it's going to be very difficult to change that belief system that drugs are not good because they make you feel so good. I was trying to get at that and I sort of did it in a trapping kind of way.

DOCTOR FISHBEIN: Yes, but we've had the same problems in the smoking area. A lot of people who smoke have very positive reasons for smoking. Some of them smoke because it's pleasurable. Now, we've just learned that smoking is also an addictive problem, even though it hadn't been viewed that way for years. The point is that we don't really know what other beliefs IV drug users have. The belief that this is satisfying and pleasurable is one of a number of beliefs they have about using drugs. There may be a whole set of other social reasons that they use drugs and these may be inappropriate and we may be able to change some of these beliefs about positive social consequences of using drugs so. It's kind of a gain, loss and net effect.

I have lots of beliefs that engaging in a behavior leads to positive consequences and I also recognize that engaging in certain behaviors lead to negative consequences. If the positive consequences outweigh the negative ones, I'm going to think engaging that behavior is a pretty good thing to do. If the negative consequences outweigh the positive ones, I'm going to think that engaging in this behavior is a bad thing for me to do.

Now, the problem with things like drugs is that the dangers tend to be long-term, down the road, they don't have immediate impact. On the other hand, the benefits are very short-term. What you're pointing out is the first thing an IV drug user may think about is how much pleasure he or she will get or that "I'm starting to hurt and I need something to take away this pain and I need that now."

But again, until we know what these people believe are the advantages and disadvantages for them of engaging in this behavior, it's very hard to know how to intervene or what to do. To assume that we can develop some broad program without this kind of informational base. That's why I'm arguing for studies to obtain this kind of information.

When I say we need studies, I would welcome national studies. But I really think that before you go into a community or a group to develop an intervention to change some behavior, have to find out what percent of the group is performing that behavior. Second, once we know what behaviors we want to change, we have to identify what the members of the group believe

to be the advantage and the disadvantages of performing that behavior. We also need to know which groups the believe support their performing that behavior, and which don't? Then we must find out whether the behavior is attitudinal or normative control. Only then can we begin to develop on effective intervention program.

So, what I'm saying is that although, I would love to see nationwide surveys, because I think that as a nation we need that kind of information, I strongly believe we need smaller studies to aid us in the development of interventions. For example, for about $20,000 one can interview small sample of any given population and find out from that sample what their behaviors are, etc. In other words, we can use a small sample to find out the sociological or anthropological meaning of that behavior for that group and then use that information to develop interventions.

Now, let me move to your second question because it's the same kind of issue. The reason that Doctor Carrera's program is so successful is because there is no fixed message or bad information. What he's doing is he's working individually with each child. He's finding out what these kids believe, what they see as the advantages of engaging in sex or not engaging in sex, what they see as the advantages of using a condom or not using a condom. He's trying to provide them with new benefits for performing low risk and avoiding high risk behaviors. He's giving them hope, if you like, but what he's doing is saying, "If you behave this way, these good things are likely to happen to you. If you don't behave this way, these good things won't happen."

Now, the good things for that community, may be very different than the good things in another community. What that community already has or doesn't have may be different than what another community has or doesn't have.

So, the program or the model that has to be moved is not, "Let's take what he's doing and do it someplace else; give all adolescents this information, give all adolescents this knowledge," but what can be transported is the approach of finding out what these kids see as the advantages and disadvantages of engaging in these behaviors; of finding out who's giving them support and who is not giving support? One must determine if it's necessary to provide additional support or to develop and realistically offer goals that these kids have never had before?"

I think that's what you can transport. But to transport that, you have to do those kinds of studies or take the time that he's taken in each community to find out in each community what the advantages or disadvantages that population

sees of performing certain behaviors. And more important, when there is little support for, or advantages to, performing positive behaviors, you have to be willing and able to develop support and create realistic positive outcomes.

DOCTOR EHRHARDT: I think in terms of drug users, it's very important that we look at the sexual behavior and the sexual transmission quite separately. We, right now in New York City, have a problem, especially with young women, increasing number of young women who are partners of drug users, who are not themselves drug users and who become infected, as we are learning rapidly in our perinatal project. It may be that what works for stopping drug use may follow different principles than what may work for changing sexual behavior among drug users.

In our center, we will have data from drug using women and drug using men in terms of detailed sexual behavior data and what can be done in terms of modifying their behavior. Our initial data from Harlem Hospital and St. Luke's as well certainly show that one can get a very detailed sexual history and communicate with drug users on their level. So, this is not to take away that, of course, treatment programs need to be and all of that, but I think we also need to pay attention to sexual behavior among drug users because that is another route of transmitting the disease.

The second point, in terms of Doctor Carrera's program, in reviewing the literature in setting up our studies at the center, there are actually quite a few of those kind of programs as Doctor Carrera's, with actually evaluation. Somehow they disappear again and they don't get the attention they should.

There's a quite exemplary program in Baltimore which was done in the '80s. It's called the Self Center Program where three schools were compared with two controlled schools. It was directed from Johns Hopkins with various community people. They were able to document -- where their comprehensive program was offered and could document that there was delay of sexual intercourse in young girls who were not sexually active yet. There also was a dramatic decrease in pregnancy in the schools who had the programs versus the control schools.

So, here was a program which had the evaluation component and showed what was necessary. For instance, the hours were important, that kids could come after hours and on weekends, that condoms were free, that there needed to be counseling, there needed to be educational counseling as Doctor Carrera suggested.

These programs which are gems somehow then disappear. They get done, they get evaluated and they are not there anymore -- nobody builds on them. That's why I was saying one of my recommendations to the Commission certainly would be that we need

funding efforts which accumulate that kind of information so that somebody who goes into those programs now can readily get that information together.

Your other question, Doctor Primm, in terms of the center. The center now works with 30 organizations in the community. I only mentioned a few. We have a community core. We are a research center so we only got, of course, limited funds for a community core. But within the limitations of our funding, we have now established a relationship with 30 community organizations.

In terms of our adolescent projects, that is particularly the shelters and community centers. We actually work in the shelters and community centers. We train the staff there. The staff comes up to our institution. We work very closely with them. We train them to do the intervention. We work with them on the evaluation so that when we would go out of those shelters after our research is done, we will leave those community organizations with the skills to deliver an intervention program against AIDS high-risk behavior.

Some of our other activities with other organizations are that the community core has regular meetings with representatives from the different organizations. We give representatives from the organizations our instruments to get input from them in terms of how culturally casually sensitive our interviews and questionnaires are. We have a speakers bureau where the community has access us and actually makes a lot of use of that. We are right now setting up a library of educational material which can be borrowed by the community. We have given technical assistance to a number of organizations to write grants, to enhance the chances of funding, which is often difficult because the research expertise is not there.

So, we are working very closely and ever enlarging in that respect. And if we will get more funds for that particular effort, we will also -- develop specific educational material, video tapes, print material together with the community organizations so that we can do health education in the best possible way.

CHAIRMAN CRENSHAW: Thank you. Admiral?

CHAIRMAN WATKINS: Doctor Ehrhardt, we were up at Harlem Hospital and Metropolitan Hospital. There's quite a debate up there about the potential for collaborative research with the public hospitals. Those two public hospitals felt very strongly they were kept out of it. Basically they were not in it. The grants were coming to Columbia and basically while the dribble was coming down, that they had the patients and you all had the money. That's simplistic but that's basically it.

They were extremely concerned that they weren't a participant, particularly in areas such as the value of research in areas of effectiveness of HIV counseling and testing with females of childbearing age, IV drug abusers who were kind of a forgotten lot in the research business. They felt that today they were providing a service without the research body of information to know whether it was any good or not, what they were doing. They want to be much more involved because they really have some burdens there. They're carrying heavy burdens and it will be increasingly so, as you know, as time goes on.

So, I'm just asking you -- you're probably not the right one, but it seems to me that when we have this kind of an epidemic, really in a national medical emergency, if you will, that there ought to be new ways to do business with the kinds of individuals that will unfortunately have to go to those hospitals for a variety of reasons, they don't have any money, they don't have any parents, in many cases, in the case of the infant AIDS pediatric situation. It's really frightening and getting much worse.

So, I'm just wondering if there isn't a better kind of a utilization of some of the sources, you might say, of the HIV infected communities that are so heavily focused in these public hospitals and give them a greater part of the research work because they have the patients and have to deal with them on a day to day basis. It seems to me you could have a double edged sword working for you in that regard.

Do you have any comments about that?

DOCTOR EHRHARDT: Yes, I do.

CHAIRMAN WATKINS: Obviously this is from their perception.

DOCTOR EHRHARDT: Yes.

CHAIRMAN WATKINS: You have to admit they're pretty heavily burdened up there.

DOCTOR EHRHARDT: Yes. Of course we are a research center and we were peer reviewed, so not all of what we wanted was also approved. Our study populations are 80 percent minority and we also made very clear that we wanted to particularly focus in on those who are in need. Now, a third of our HIV center is adolescents. So we are really working very heavily with the innercity shelter and community centers.

Then we chose one hospital which is very burdened and that is St. Luke's, in terms of the perinatal project. That

project will include several hundred women, almost all Hispanic and black. We had to make a choice, of course, in order to find the way to make a collaboration possible there.

In terms of the IV drug users, as you can imagine, to set up a center like that -- and it was quite the opposite when I started to set it up. I had to beg people to come in. Now, that we have the money, everybody would very much like to participate. worked day and night to get people to write a research proposal to set up such a center. Some of the people which you heard in New York withdrew from the effort two days before the proposal went in.

So, we have some restraints, but we are making every effort. We are working on the assessment of testing. We are working on a proposal, for instance, with Doctor Curtis right now. We are trying to work on a proposal as an add-on project to the center to evaluate how -- which is his particular interest -- to evaluate the effectiveness of testing. Of course we have the restraint whether we will get funded or not and whether he will get funded or not.

So, yes, we are very much aware. I'm sure you also can imagine to set up a center which includes four different hospitals and ten different disciplines and many different shelters and community centers is a major undertaking. There will always be people who feel left out. New York City is so heavily burdened that you could -- ideally you may want to have three HIV centers in New York City in order to be able to include the different groups and hospitals. But we are doing our best.

In Metropolitan Hospital, for instance, the community core is trying to give technical assistance to get more funds, to develop proposals.

CHAIRMAN WATKINS: One of the big concerns they expressed was the fact that not being a teaching hospital, they aren't very well equipped, frankly, to be responsive to the request for proposals. They have a different expertise, they don't staff for that kind of thing. And so they sit there somewhat feeling like orphans in a larger system. Is there a way that, for example, the major teaching hospitals can help them write those proposals?

DOCTOR EHRHARDT: Yes, we are doing that.

CHAIRMAN WATKINS: Are you doing that now?

DOCTOR EHRHARDT: We are doing that now. We are giving technical assistance to several groups within our community core. I think that's exactly what researchers at an

institution as mine can do. That's one of the functions we can do and we will certainly increase our efforts in that respect and certainly want to do that.

CHAIRMAN WATKINS: They want to be involved in the behavioral change patterns and they want to be up to date. They want to be participants, they want to be players. They've got heavy loads of HIV infection in their hospitals. They are struggling at the edge of financial disaster. They're doing many things and I think this is a time when we may need to reach out a bit more and expand the participatory effort which has to go almost in parallel because of the numbers flowing in. We're not at a point when we can say, "That's the best and that isn't." We have to do the best that we can at the present time and allow them to participate in that so that they move along with you.

I would just encourage that kind of participation. We were rather impressed by the dedication and the commitment there without much resource, particularly when you get into perinatal AIDS where virtually the surrogate parents, because there were very few other identifiable parents, are interns, cardiologists, incredibly high skilled individuals who are actually in a nursery with 47 cases. So, those are the kinds of things, I think, that generate the emotion in such a thing. I would just encourage that kind of enhanced collaborative effort.

DOCTOR EHRHARDT: Well, we will do our best and even do better.

CHAIRMAN CRENSHAW: Thank you all very much. I'd like to summarize by saying that there seems to be a consensus on the panel, and I'm including Doctor Carrera who is no longer here, that an integrated program is not only desirable but essential to make a meaningful difference. It's unfortunate, as he indicated, that in the very beginning of sex therapy they took more of a genital or technical approach. I think that aura still lingers.

I recently saw something in U.S. News and World Report that suggested that sex therapists were still just mechanics. I think you've demonstrated through your comments today that is not the case. But it takes a long time for early impressions to fade. Now, it seems to me that what we need is to pursue these integrated efforts where we deal with all facets of feelings, emotions, family, love, sex, in context rather than excerpted as something unfamiliar, foreign and threatening to the community.

I'd also like to say, and I complement you for not saying it actually, that the failures of many of our sex education courses in place right now have a great deal to do with the fact that there's no funding for training teachers as you expressed, that there isn't even funding for books, that normally

they're working from syllabi. If you tried to teach history or math the way we've been forced to teach sex in schools, which is that you can't answer questions, we wouldn't have many readers or many people who could add or subtract.

I think that if we get the support that this HIV epidemic is forcing to be there so that this area gets appreciated and gets done right, that the future can show a very different track record than the past. I thank you for being here to share these thoughts with us. Yes?

CHAIRMAN WATKINS: I should have mentioned this when Doctor Carrera was here, Ms. Tatum, but there's hope. The Senate and House passed a new primary and secondary education act of 1987 with the new provision under the Title II reauthorization. It's one of five targeted programs nationally and it's called Personal Excellence. For the first time in an education bill that I know of, it includes grants to states who can pull together a holistic approach in any area, region, whatever. It deals with health education, health promotion and fitness of young people and motivation of young people. The motivation aspect is what Carrera's involved in.

It's the horse before the cart, we all know that. We have to get some kind of hope back in the minds and self-esteem and worth of those people as special children of God and those people can come alive then and begin to take advantage of access to health care and the other things that are so important and the availability of the teachers that can deal with this in its most fundamental context so that we have a place to put these kinds of behavior change elements.

It's the first time it's appeared. I doubt if anybody knows about it. But you seem to be a wonderful spokesperson for holistic approaches, so why don't you get the state of Virginia going. You've got the right governor to do it. He's interested in education and health and maybe it's time to start moving the nation and demonstrate by some role models in some of these areas, and giving them the resources they need to continue and to demonstrate.

We want to go as far as we can with the leadership we have. How can any of those things be bad? So why don't we pretend that they're really going to work and at least we'll eliminate some of the variables in the complex equation that we're trying to deal with here. But there is a recognition now that health education, health promotion in the schools may have to be a curricular issue and maybe fundamental to the education process. Some people seem to think it is and should be today.

So I think these are the kinds of things where we don't want to lose any of the momentum that the HIV epidemic has

catalyzed in a positive direction to respond to it. So I mention that here because it's coming along and you mentioned that things are beginning to gel and take shape nationally on this whole set of issues. I believe that we're going to be coming out in our report with certainly a vision of what this country is as seen through the lens of the HIV. It's drastically in need to change in many areas, fundamental education which includes health education, health promotion, and certainly those concepts of human dignity that give people a chance at some hope that when they get there they're going to have a place in society.

So, anyway, I think that you all gave us, or certainly gave me, some additional inspiration in that area because now we've heard it from too many people coming before us that we've exposed a larger ill in society that we've got to deal with at the same time and there's no reason to say, "What do you want, one or the other?" We can solve them both, in my opinion.

CHAIRMAN CRENSHAW: Thank you again and we will reconvene at 1:15.

(Whereupon, at 12:43 p.m., the above-entitled matter was adjourned to reconvene this same day.)

A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

1:35 p.m.

PANEL 3: THE FEDERAL ROLE

CHAIRMAN CRENSHAW: Doctor Judd?

CHAIRMAN WATKINS: Just one witness.

CHAIRMAN CRENSHAW: That's right. We do have this separated, although, Doctor Judd, when the remainder of the panel members come up we're hoping you'll be able to stay and join us for the question/answer session. So, I have misled you. I have led you astray.

The remainder of the panel members, if you'd wait until Doctor Judd's testimony is over we'll set up name tags for all of you.

Come join us, Doctor Judd. I didn't notice their name-keeping system here.

Doctor Judd is the Head of NIMH, and is going to talk to us about some of his clinical and research issues as well as particular matters that reflect upon and influence positively and otherwise the behavioral therapeutic interventions we're trying to make more successful.

DOCTOR JUDD: Thank you very much, Doctor Crenshaw. It's a pleasure for me to be here and to speak before the Commission.

I have submitted a written testimony for the record, and what I'd like to do in the brief time that I have available this afternoon is to, one, introduce you to the National Institute of Mental Health, which is a scientific institute in the federal government charged to study the etiology and treatment of mental disorders. Our expertise, as a scientific institute, really does reside in the areas of studies of brain and behavior as they relate to mental disorders.

In addition, I wanted to cover in a highlight form, an outline form, the research program in AIDS that is being mounted by the National Institute of Mental Health which we feel is rather unique in terms of federal response to the AIDS crisis, and we feel makes a complimentary contribution to the other scientific institutes in the federal government.

In addition, what I would like to do in covering in a general sense our research portfolio and to highlight the major thrusts of the program, because I understand that this particular panel today is focused on issues of behavioral studies and studies on behavioral change that I might deal with those in a little bit more detail. So, what I will be prepared to do is just talk informally about that and then answer any questions you might have or I could join the panel, whatever you'd like me to do at that point.

First of all, the design of our research portfolio on AIDS really comes from within the scope of what, by history and by design, our scientific expertise is. It ranges from basic studies in the neuroscience on out to studies involved with behavior change and attitude change and the use of these in new prevention models to curb and control and shape high-risk behavior.

First of all, let me go from the basic to the more applied. We have -- it's become very clear in the last few years that the HIV virus is a neurotoxic virus, one that attacks the brain early, and we know at least late in the course, rather devastatingly. We have felt that it's been important for us to do some basic studies in the neurobiological mechanisms with regard to HIV infection in the brain and then to relate those phenomena to clinical phenomena and relate it to the abnormalities that appear in behavior, cognition, and affect and mood that we know now is an integral part of the course of progression from seropositivity on to the AID Syndrome.

We feel that at least in this one area there is a very important public health question that remains to be answered. Specifically, we now know as of the last few years that since AIDS does have a proclivity to the central nervous system and we know that dementia now is a part of the AIDS syndrome added in the last year.

Two studies have come out rather recently focusing on the beginning of the so-called dementia in AIDS. At least two studies have indicated that there may be a change in cognitive function when one converts from sero-negativity to sero-positivity, even before symptoms occur. So, we feel that this is an important area of study. It remains an empirical question, and we have basic and applied studies focused in this direction to hopefully develop within the next few months, and maybe six to eight months for certain, an opportunity to provide information on which rational public policy could be based.

Right now, this very day, the Institute is sponsoring a conference on the NIH campus which is focusing on neuropsychological studies in HIV infected individuals to review

the current status of what we know at this point, and secondly to develop if they can an agreed upon neuropsychological battery which will allow us to look at this issue in much broader populations and with larger subject samples across the full AIDS spectrum. That's one area that we're focusing on.

Another area that we're focusing is in psychoneuroimmunology. It's become very clear within the last decade that the brain is very fundamentally involved in the regulation of the body's immune response. We're looking at some fundamental studies in trying to delineate and characterize how the brain might regulate the immune system and to also get a clearer understanding of how the brain serves as a mediator with regard to the immune response of the body.

It's very clear that the brain is very importantly involved in apprehending and understanding and reacting to environmental stress and also the brain is an important mediator in the behavioral studies that we're conducting with regard to modification of immune response in regard to helping to ameliorate stressful events and their impact on the immune system.

Another area that we're looking is in the development of new treatment technologies and techniques in the treatment of AIDS. I know you're all aware of Peptide T. Just to briefly encapsulate that, this was discovered by NIMH neuroscientists who found a receptor site for HIV both in the central nervous system and on the lymphocyte, the T lymphocyte. They followed this up by characterizing the receptor, found out that it was a site where a naturally occurring neuropeptide also bound, and then used this as a model to actually chemically and molecularly engineer a peptide that would block the entry of the AIDS virus, at least to the neuron. That is currently under study.

I'm only mentioning that because of one decision that's been made within the Institute, to keep a diversified scientific portfolio within the scope of our expertise. Because, it's very clear that breakthroughs with regard to treatment of AIDS and understanding of AIDS at this point it's not clear exactly where it will come from, and I think none of us would have predicted a year or two ago that a potentially promising new treatment would have emerged from basic brain studies.

Another area that we are focusing on is in characterizing the clinical course of the behavioral and neuropsychiatric and cognitive abnormalities that occur across the AIDS spectrum. Specifically, what we're looking at in this regard, we well know at this point from studies sponsored by the NIMH that in regard to conversion to sero-positivity that a number of individuals become depressed, despondent, and despairing over this.

We feel it's very important to characterize this. One, is this a true depressive disorder? Is it primary in nature? That is, is it an outcome of CNS infection or is it a reaction to the presentation of a life-threatening illness? So, we're attempting to characterize this, to follow it, and then we have a series of controlled studies in place to actually study intervention techniques to see whether they work well or do not work so well.

In addition, we're about ready to initiate a series of controlled studies in looking at the treatment of AIDS dementia right now. We've found that a number of individuals are using a CNS stimulus to treat AIDS dementia. Now, that may be a short-term gain. It may be a long-term problem. So, we feel that this is important to do this in a controlled way so that we can put out strong and documented research-based information to the field to respond to this particular problem.

The one area of our portfolio which really constitutes the bulk of the NIMH's research effort on AIDS is in the area of behavioral studies and in the area of studies to attempt to change attitude and following that to change behavior regarding high-risk behaviors that contribute to the spread of the epidemic. Since we do not have a vaccine, it's very clear that a central response, a responsible response, is going to involve an attempt to curb the spread of the disorder.

Approximately 60 percent of the NIMH's current portfolio is devoted to research in this particular area, and we've been reviewing it over time. We're very interested and hopeful that it will begin to make impacts. I would say that in some ways it's been a very positive picture.

In other ways, there is much, much more to be done in this regard. Even though the NIMH cannot take full responsibility for this, we were involved both certainly in San Francisco and in New York in helping impact the gay and bisexual male community there to provide them with solid, rational, and good information as to what behaviors were spreading AIDS at that point, what they might do to avoid it. We worked rather carefully through certainly the AIDS Center at UCSF with a rather strong gay leadership group in San Francisco.

I would say that the data that's emerging from this is rather encouraging. There have been marked changes in sexual practices among this particular group with regard to increased use of condom, decreased unprotected anal intercourse, and in fact there is evidence that at least in two cohorts we are following in that area that the conversion to sero-positivity has diminished enormously. In 1986, it was around 2.3 percent -- new cases coming in at that point in this particular cohort. In

1987, that was down to .4 percent, and we're ready for data for this year -- we'll see how that's going.

So, we feel that we've had a -- at least along with others we've played a role in this, an impact on this. Right now it seems that at least in the San Francisco area there are relatively few new cases of HIV infection of individuals in the gay male and bisexual group at this point.

What is particularly concerning and alarming, and I'm sure you've heard this from other testimony, is that there are other high-risk groups that we have not had the same kind of impact on. First of all, IV drug use is a major problem. From our surveys, approximately 25 percent of the HIV infection in this country really is emanating from the use of unclean needles. This group we are just beginning to zero in on. In a sense, it's been defined as not a new but an emergingly important high-risk group.

We have strong collaborative efforts with the National Institute on Drug Abuse, which is our sister institute in ADAMHA. We are beginning to try to characterize the group. Approximately 77 percent of them come from minority group membership, both black and Hispanic. It is a group that tends to be from the lower end of the socioeconomic spectrum and a group that tends to have lower educational status. So, it has not at this point been as amenable to our attempts at intervention, although we are looking at it very, very closely. It's a very particularly concerning population, because 80 percent of the pediatric AIDS cases are coming from -- it seems to us, are coming from this particular group through the partners of male IV drug abusers.

Another group that is emerging as an important high-risk group that we now should begin to concentrate on -- there are a series of studies that are actually in place through our AIDS centers and through investigator-initiated awards -- is the minority gay and bisexual population.

Another group is the adolescent population that's just emerging into sexual experimentation who potentially might be a reservoir of high-risk because of lack of information in what is safe sex practices.

Finally, there are two other groups that have emerged of interest to us. One is individuals who use alcohol and drugs during sex in a combination. Those individuals show, at least from our surveys, a two and a half times increased incident of unsafe sex practices. In addition, that seems to vary by drug. For example, if one uses a CNS stimulant, an amphetamine, that goes up to three and a half times.

In addition, we were able to contrast bar populations in a very preliminary look at this in the San Francisco area, in which the behavior of the gay male group was rather responsible, but there was a rather irresponsible group who were using alcohol rather heavily in the bar and then meeting people and going out and practicing, at that point with a high degree of risk, unsafe sex. So, we see that as another area that we will be focusing on.

Finally, an area that is highly germane to the Institute that we know very little about and we're attempting to initiate some studies along this line is actually the mentally ill, the chronically, seriously mentally ill individuals who know very little really at this point about their sexual practices and very little about the incidence of HIV infection. Clearly, that subpopulation of homeless, we don't know much about them either at this point. We feel that these need to be corrected.

So, with regard to behavioral change we have had we think an impact, and a notable one, and one that I think that we can take some comfort in. But, in the process of this we've identified additional high-risk groups that need a careful look and will probably very much need highly tailored messages.

The one thing in reviewing the impact that we contributed to in San Francisco was the advantage of having a strong leadership group within the gay male group there. Secondly, a blitz almost in terms of information being brought to them through multiple channels, through media, through publication, through communication through group and on a one to one basis, that appeared to be extremely helpful. And one of the important features of changing that was that the norms of that particular group began to change, and that seems to be one of the important features at least in our early experience in behavior change with regard to increasing the likelihood of inducing behavior change.

So, I won't take any more time at this point with regard to the oral testimony, but I will be pleased to answer any questions that the Commission may have.

CHAIRMAN CRENSHAW: Thank you very much. I appreciate your willingness to remain with our other panelists. I would like to have them join us now and then we'll save questions for the end, when we can perhaps have them in context.

The sequence has been changed and you're seated so I don't want you to get up, but I'll let you know in which sequence we'll be having the testimony.

PANEL 4: THERAPISTS' ROLE IN PREVENTION

CHAIRMAN CRENSHAW: I'd like to introduce this panel by saying that therapists of sexuality, marriage and family therapy, psychology, and psychiatry, are not ordinarily considered to play a key role in public health issues, or for that matter even education and disease prevention. But, the AIDS epidemic has changed a lot of things and this is one of them. We have spent a tremendous amount of attention and not nearly enough on dealing with groups at risk and high-risk groups, and we have spent some time and not nearly enough on looking at the general heterosexual population with a concern for keeping low-risk groups low.

So, the focus of this panel, although you won't have heard this subject raised so often, is going to be to look at what each discipline can do in therapy, what their opportunities are, what their responsibilities are in keeping low-risk groups low, in dealing with the everyday patients that come in, what a therapist can do to intervene in behavior that they identify in a patient or in a client as putting that person at risk for their health.

It's a tremendous resource that reaches millions and millions of people who have sex with millions of other people. Fortunately there have been some leaders in the field giving us knowledge and raising our awareness and our consciousness.

I'd like to begin with Doctor Goedert, who has been dealing with what's become a new term, or at least new to me, discordant couples, particularly in hemophiliac cohorts. I don't know if he originated the term or borrowed it from elsewhere, but he is going to talk to us about his experience with the hemophiliac couples.

DOCTOR GOEDERT: Thank you very much, Doctor Crenshaw. It's a great honor and privilege to be here to testify.

I think if anything I perhaps serve as a little bit of a transition from Doctor Judd to the therapists themselves as a physician and a medical oncologist cancer specialist by training. I've kind of gotten more into research and epidemiology as a practice, so I'm not literally a therapist myself but have an active research interest in the epidemiology of AIDS and HIV disease.

I apologize, my testimony wasn't ready until 10:00 this morning, and so I don't know if you've got copies of that. To same time, I'm going to read through parts of it and then I'll be happy to answer questions.

Since a safe and effective vaccine to prevent human immunodeficiency virus, HIV, infection is not likely to be available for the foreseeable future, programs to interrupt the transmission of HIV through prevention are essential. Such programs must take root in the epidemiology and biology of HIV and AIDS, must be nourished by various disciplines such as psychology, sociology, mass-marketing, and others, and must be protected from subversion by any who would use AIDS as an excuse for discrimination.

After seven years of study, a great deal is known about the modes of transmission of HIV and the natural history from virus infection to disease. As part of our efforts to contribute to this body of knowledge, in 1987 I outlined a program to reduce sexual transmission of HIV which defined a set of standards for truly safe sexual activity that were linked not only to behavior but also to testing for HIV. This approach differed from previous education efforts in three respects.

First, if emphasized that HIV is so insidious and lethal that the appropriate goal should be to eliminate, not merely reduce risk; thus, the need for standards rather than relative scales of sexual behavior.

Second, the approach I outlined pointed out that protective measures during sexual intercourse were unnecessary for many persons, specifically monogamous drug-free couples, when both individuals have concordant, that is negative-negative or positive-positive HIV antibody test results.

Thirdly, it proposed the bitter message that uninfected individuals in an HIV antibody discordant or-unknown relationship were unfortunately truly safe from HIV only if they abstained or limited their sexual activity to behavior which does not involve exchange of any potentially infectious bodily fluids, such as mutual masturbation.

Because of inherent failures, condoms in my program were relegated to secondary risk reduction measures. Although meticulous use of latex condoms with a spermicide for every episode of intercourse is likely to reduce the risk of HIV transmission markedly, condoms are not foolproof. Those who would use condoms must understand that meticulous use of condoms will reduce, but at least with current technology not eliminate the risk of HIV transmission. Condoms have failed to prevent pregnancies, and in individual couples have failed to prevent HIV transmission.

Moreover, three studies of heterosexual partners of HIV infected individuals could find no benefit to irregular use of condoms. In my opinion, these data argue that couples with discordant HIV status should be counseled that risk elimination

is possible only through abstinence or when sexual activity is limited to mutual masturbation or similar external activities.

Similar frank, honest counseling that condoms are likely to reduce but not eliminate risk should also be considered for sexually active HIV unknown couples, including any untested individuals and those with ongoing risks such as non-monogamy or parenteral drug use.

In Hurst and Hulley's calculations for a low-risk heterosexual population, condom use was far less effective than knowledge that the partner had even one negative HIV antibody test.

From some of our newer data, we have postulated that although the size of the HIV-infected population in the United States may not be growing rapidly, the infectiousness of this population may be increasing.

Specifically, we identified six steady female sexual partners of hemophiliacs who became infected after four or more years of sexual contact. Two of these women became infected coincident with their male partner developing extreme immune deficiency. And we noted that very low numbers of T-4 lymphocytes in the men appeared to be a significant surrogate marker for HIV infectiousness.

We have subsequently expanded the study to eight hemophilia centers and have noted that 14 percent of the enrolled women had HIV antibodies. Heterosexual transmission was noted to be infrequent, meaning one percent or less during the first three years of sexual contact with an HIV-infected hemophiliac, but the rate increased to four percent or more per year during the fourth and subsequent years. Risk of heterosexual transmission was generally unrelated to types and frequencies of sexual activities, but strong risks of heterosexual infectiousness were noted with biological markers in the men, not only very low numbers or proportions of T-4 cells but also presence of HIV P-24 core antigen in his serum.

I must emphasize that these are indirect and imperfect markers of infectiousness as they did not identify every instance of heterosexual transmission. However, they do provide insight into the biology of HIV transmission. In addition, they herald assays of improved sensitivity that are likely to assist in the identification of highly infectious individuals for whom behavior modification efforts and perhaps treatment efforts should be targeted.

Educating the population that HIV is a heterosexually as well as a homosexually transmitted agent is a critical first step, but a comparatively easy one. Far more difficult to

overcome will be denial of personal risk, negative associations and inaccuracies about the validity of the HIV antibody test, and lack of sufficient motivation for substantial alterations in obviously risky behavior.

Distortions about the HIV antibody test can be countered by forthright presentations of correct information, by adamant resistance to discrimination against HIV-infected individuals, and by rigorous quality control and validation procedures to minimize the rare but potentially tragic consequences of incorrect HIV antibody test results.

Motivating substantial behavior changes is probably the most difficult problem of all, irrespective of the approach taken. This is the case even in highly educated and counseled populations, such as our study cohorts of homosexual men and hemophiliac female partner couples in whom obviously risky behavior has been discontinued far too late, frequently after HIV transmission has already occurred. We have a very clear responsibility to motivate behavior change not only for those at highest risk, but also for those with a lower risk.

Many innovative approaches to reduce the incidence of HIV infections in the United States should be attempted. Every intervention program must have as its foundation the biological and epidemiological facts of HIV. Every approach must also respect the rights of individuals, without which an intervention program is likely to do more harm than good. In addition, the effects, negative as well as positive, of these programs must be evaluated by actual data collected from the target populations. Without such, five years hence we may still be groping for optimal educational strategies.

I have proposed one approach to reducing HIV incidence in the population by stressing standards of truly safe sexual activity that link individual behavior to a couple's HIV antibody test results. This safe sex program apportions responsibility to all segments of the sexually active population. The greatest responsibility is placed on HIV-untested and HIV-positive individuals, but HIV-negative individuals cannot deny responsibility either and must recognize that sexual activity outside of drug free monogamous relationship poses genuine risks for one's self and one's partners.

In return for accepting these responsibilities, the vast majority of couples can engage in worry free and AIDS free sexual activity.

CHAIRMAN CRENSHAW: Thank you very much, Doctor Goedert.

CHAIRMAN CRENSHAW: Doctor Kaplan?

DOCTOR KAPLAN: I'd like to echo Doctor Goedert in expressing my feeling that it is a real privilege and an honor to be able to speak here, because we still have an opportunity to prevent a massive epidemic. I have also prepared a written testimony, so I will just highlight the contents of the written testimony have. Shall I introduce myself?

CHAIRMAN CRENSHAW: Please do.

DOCTOR KAPLAN: I'm Doctor Helen Kaplan. I am a Professor of Psychiatry at the New York Hospital--Cornell Medical Center, in Manhattan. And I am also the Director of the Human Sexuality Program at that institution.

Therapists, especially sex therapists, because of their special expertise in human sexuality and experience in modifying sexual behavior, could play a vital role in preventing the heterosexual spread of AIDS, or of HIV infection. Therapists exert an unusually powerful influence on their patients, because patients tend to transfer parental attitudes, "father knows best" attitudes to their doctors. They themselves tend to regress to a childlike trusting position, and they often do, what the therapist advises them to do more or less uncritically. We could use the power of transference for the benefit of these patients. That is a potential lever for modifying their sexually risky behavior. I will highlight some specific issues. The therapeutic techniques which are available are more fully described in my written testimony.

First and foremost -- again, I'd like to echo Doctor Goedert's really wonderful remarks -- we must provide patients with accurate information about the sexual transmission of AIDS that, are based on the biology and reality of HIV. People can make informed choices and protect themselves only if they have accurate information.

But, unfortunately, because new information in this field is accumulating so rapidly and there is such a political struggle about the HIV epidemic, the public has been exposed to very confusing and often inaccurate information which is potentially dangerous. I will give you three glaring examples.

One, which Doctor Goedert already mentioned, the safety of condoms has been greatly exaggerated, giving the public a false sense of security. People really think as long as they wear a condom they can safely have sex with someone they don't know. But, the HIV virus and infected cells are not only in the semen. They are in body fluids. So, even if the condom worked perfectly it would be more like using a filter cigarette to reduce the risk rather than stopping smoking, which would eliminate the risk.

Two, HIV testing. One of the most accurate tests used in modern medicine has been maligned and undermined by much false information that has been disseminated in the media.

Three, possibly the most confusing myth is that exposure to the HIV virus and infection is the same thing. They are absolutely quite different.

Exposure merely means that a person has engaged in some sort of high-risk behavior and could have been infected. At this time, if they are non-drug using and heterosexual, the chances are still very small. But, persons who have been exposed should be tested and cleared to protect their future sexual partners.

On the other hand, infection with the HIV virus is very serious. It means the virus has actually invaded the cells of the person's body and the person is infected and infectious to others, presumably for life, even if he or she doesn't have a single symptom. Most infected people are healthy and, sexually active.

I couldn't agree more with Doctor Goedert's point that we must -- for the heterosexual, low-infected, non-drug using populations stress elimination of risk, rather than reducing of risk.

Risk reduction policies make sense for the highly-infected homosexual, and drug-using populations, since the majority of those risk groups are infected in certain locales, whereas the infection rate of the general population, the heterosexual, is still extremely low. Heterosexuals have different sexual behavior patterns. They are much less likely to have as many partners as the gay community, and they are likely to know their partners better. This is what the research has shown in study after study.

As Doctor Goedert said, there is no such thing, as a member of entirely safe sex, with or without a condom, if your partner is infected. On the other hand, if the partner is not infected, there are no virus particles in the body fluids and the cells, then everything is safe. Vaginal sex is safe. Anal sex is safe. Oral sex is safe. The main point that should be emphasized in prevention and education programs, which target those who do not use drugs and who are heterosexuals is to eliminate the risk. That is the only policy that makes sense for the majority of Americans is to eliminate the risk.

Therapists have the technology, the know-how, the training to modify people's risky behavior and to identify and avoid sex with an HIV infected partner.

Therapeutic techniques are available to pierce denial and this is important, for it is only natural for people to deny the dreadful consequences of HIV infection, and to take an "I don't want to know" attitude. It is our obligation to raise the public's consciousness to the fact that if they have been exposed, it is their moral obligation to be tested and cleared before they have sex with and infect someone else.

We have the techniques to promote and to effect high quality monogamous sex. It is entirely possible to maintain sexual passion within a sexually exclusive relationship. But there are many people who are unable for psychological problems, because they have certain psychological problems, to experience real sexual passion with a single partner. And they, of course, are driven then to have multiple partners which can and the techniques to modify this type of behavior.

What are the obstacles to putting these policies into effect?

A: Except for sex therapists, most health professionals are really not very knowledgeable about sex and about the sexual transmission of AIDS and they really not have sufficiently accurate information to advise their patients correctly.

B: Politics has polarized the mental health field so that there is a group of therapists who feels more compelled to protect the sexual freedom and the confidentiality of their HIV infected patients than to carry out their sworn duty to protect patients and their families. A good step in the direction of protecting partners was recently taken by the American Psychiatric Association. We passed a resolution that it is the physician's moral obligation to notify the partner of an HIV infected person if there is no other alternative. Of course, first the doctor should try to persuade the patient to inform their partners. But if there is no alternative, it is our obligation to inform the partners.

Finally, negative social attitudes about AIDS are tying the hands of public health officials and therapists. There is much to be gained by re-defining AIDS, which suffers from social stigma, as HIV infection, which is a more valid term. Also, if HIV infections were made reportable, it would free us to, use proven public health measures such as contact notification (without which you really cannot stop a sexually transmitted epidemic) to reduce the spread of HIV infection.

Before I end I want to say a word about women and AIDS. I noticed Doctor Judd was identifying new risk populations. Well, women are not highly infected yet, and our public health policies were never designed with women in mind. Yet we are

directly in the pathway of the oncoming epidemic. And women have a double jeopardy. Not only is a woman who is infected with HIV just as likely as a man to get AIDS and die, 50 percent of all her future babies will be born with AIDS to die. And apart from the benefit to women and children, whose health certainly should be protected, you have to remember that AIDS at this time in the United States is still predominately a male disease. Over 90 percent of patients that have AIDS are male. Most of these -- infections is confined to two highly infected small pools of homosexual-bisexual men and male IV drug users. Actually, homosexuals pose no direct threat to the general population, because they have sex with each other only. But what not usually understood is there are from three to five times as many heterosexually active bisexual men as there are exclusive homosexuals and that poses the greatest danger for women.

Women form a bridge, actually the only bridge, by which the virus can cross out of the two small infected pool of males via sexual transmission into the general population. And for these reasons I would really urge you to aim future public health policies towards the special needs of women and their yet unborn children. Thank you very much.

COMMISSIONER CRENSHAW Thank you, Doctor Kaplan.

COMMISSIONER CRENSHAW Doctor Schwartz?

DOCTOR SCHWARTZ: I'll introduce myself first. I'm Mark Schwartz and I'm an Assistant Professor of Psychiatry, Neurology at Tulane University. Formally I was Director of Research at Masters and Johnson Institute in St. Louis. And currently I'm the Director of an institute in New Orleans where we deal with compulsive sexual behavior.

For the past several years we've run an inpatient and outpatient program for individuals involved with compulsive sexual behavior and we've been pulling people from all over the United States to New Orleans for this sub-specialty program. Typically the program we're running is about 30 days from people from out of town.

In that program I have probably have worked with hundreds of individuals who have been sexually out of control. And what I'd like to be able to do today is tell you a little bit about who they are what an why they are out of control sexually, something about their backgrounds, and how to stop this behavior.

I think the good news is that we've been effective well over 90 percent of the people we've worked with in getting them under control and keeping them under control. I think the bad news is that simple minded intervention of attempts to provide the education by giving information giving or coming down with a

very negative kind of approach of attempting to somehow discourage people from homosexual behavior or discourage people from "being promiscuous" is going to be totally ineffective.

Let me first tell you a little bit about who these people are. A lot of the population I work with are bisexuals who have been completely out of control. They get referred to me a lot by the courts because they get picked up in one of the city parks on a frequent basis or in book stores where they make raids or in baths. These individuals are often of high standing in the community. Some of them are clergy. Some of them are politicians, some of them are doctors, lawyers and businessmen of high visibility. The reason I emphasize that is because there may be some idea that we're talking about some sort of low life individual whose involved in this and it is certainly not true.

These individuals are having four to five homosexual encounters in a day, some of them much more than that. And many of them go home to their wives and children following their activity or they do it while they're out running or jogging in the park on a frequent basis. Let me assure you that this has not stopped, that you can go to any park in New Orleans and find yourself a homosexual trick, if that's what you're interested in. You can still go to the gay baths and there is still ample opportunity on the streets.

I think the emphases of the press that the behavior of these individuals has changed is because the bisexuals are a silent group. That is, that you will not specifically be able to identify these individuals you want to reach them through education, and there is no way to other than to focus on the broad heterosexual population in general.

And you want to know why it is that they do this. For those of you in here, perhaps, you think well all we need to do is think logically and rationally and if we tell them that they have the threat of killing themselves or their family, that they'll stop. Let me assure you that is not true. These are rational individuals. But the problem is that they're out of control. The analogy to conceptualize this is like that of any addictive behavior.

The most interesting population to compare them to would be the adolescents that you heard about this morning. Years ago we learned that it was ineffective to sit down and talk to adolescents in a rational, logical adult manner and telling them the troubles of having sexual intercourse without proper protection. The fact that we have a million teenage pregnancies or more a year is proof that this technique not stop adolescents from having sexual activity. I've talked with adolescents who have had two or three abortions who swear that they can't get pregnant.

Now, they're not crazy people. They just think very differently. And so what we have to look at is the way people think and the way to change people's thinking when they get out of control.

The bisexuals that come in to see, say that they didn't ask to be gay, looking at the homosexual side of their behavior. They say was something that was sort of put upon them. It's not something they have ever wished for in this homophobic society. And there's nothing they can do about that, that that's just who they are. And then they generalize this attitude out to all of their behavior and they say if it's out of their control in the fact that they are homosexual and didn't ask for it, then I'm not in control in any part of my behavior. And so if they go out and five tricks in an evening, they say: "I can't help it; it's just because I'm gay."

This generalizes on, the attitude is: if I get positive HIV or AIDS, then maybe it's meant to be because I didn't ask to be gay, I didn't ask for AIDS but if I catch it, maybe I deserve it. Because of the tremendous public prejudice against homosexuality, they've internalized this with a great sense of shame and so some individuals feel at some level almost a sense o wanting to be caught and punished. As though somehow they're putting themselves and their fate in God's hands, so to speak, and they're saying: "if I get AIDS, I'm being properly punished for being a bad person. And so they're playing Russian roulette with three bullets.

The reason I say three bullets is because they cut their activity in half now. They used to play it with six bullets, now they only play it with three bullets by having less activity because of the fear of AIDS, but they simply haven't stopped. They also evidence denial by saying things like, "Oh, I always have safe sex." Let me assure you that that is false. That what we know about people's sexual behavior is that in the heat of passion they do things and they say, "Well, you know, I couldn't help myself. I was out of control." And so for years people have had pregnancies or spread venereal disease because in the heat of passion they couldn't or wouldn't control themselves.

So when they say they're using safe sex, what they really mean is that they usually use safe sex. And if they say that, it doesn't mean that they're not exchanging bodily fluids. It often means only that they're not having anal sex.

So this whole thing about safe sex is something that is confusing. Compulsive say they are having "safe sex" as part of their system of rationalization and denial, which is what addicts do when they're out of control, to be able to continue their activity the way they've always done it.

Now what about the backgrounds of these individuals? Let me say that these individuals are not individuals who have typically psychiatric illness. They're not individuals who are disturbed in any major way. One thing you find uniformly in these individuals is that there have been secrets in their backgrounds. For example, the mother has been sexually molested, or their father had a severe brain tumor in the middle of their childhood. In other individuals there was some sort of sexual secret, an affair that his father would have on a regular basis which he knew about, and so on. In other words, in the families of these individuals what you find is that there has been some trauma usually associated with sex that's been a secret. And that secret has been then transmitted on to the next generation. And so what we've been doing is a lot of work with their previous families. And that -- is necessary to be able to get these individuals under control.

Now, how do you get these individuals under control? There are numerous components to treatment. One of the things we do is we bring individuals into a support group, into these support groups. Everybody in that group is under control and they make a contract to stop their activity. Almost uniformly when people stop their hypersexual activity, what they find out is that they go into a severe depression or anxiety disorder. Sometimes they become suicidal. They've been medicating their own depression by having sexual activity.

So when they do that, what we often times do use psychiatric medication to be able to help them through that phase. Once they get beyond that and they find out they can get under control, there are techniques which we recall relapse prevention techniques which we've been using from the addiction fields to help these individuals get under control and maintain their control.

Most of all what we do is to take the rationalization or denial systems, like you would with any addict, and blow them apart and help them begin to get out of what we call their "dissociative fog" or their "thinking errors" and begin to show them that they can have a committed monogamous relationship with another person.

We believe these individuals have what we call intimacy problems or intimacy disorders. And we think that the key element is getting them in as couples and begin to show them that they can maintain a monogamous relationship on a consistent basis, and that they can make a commitment.

What are the implications of this on a larger scale? Certainly a therapist can only see a small number of individuals. It's not unimportant because any lives we save are going to be

important. And believe me, I have saved many lives because a lot of these individuals would have come down with positive HIV status. And when they've discovered their positive HIV, they would have transmitted it on to many other individuals. We have and numerous people coming in with positive HIV and when they get that, they don't stop their sexual activity. They continue it. So these techniques have been useful with them.

What I think the implications are is that, number one, that any kind of simple education alone is not going to be useful in hitting a large part of the population who are sexually out of control. We learned this years ago with teenage pregnancy. We can certainly use innovative programs such as the ones you've heard about this morning to stop teenage pregnancies. But on a population scale, it's just a small amount. We still have large amounts of teenage pregnancies despite many very good sex education programs. There are many reasons for that, which you've heard this morning. But, nonetheless, simple education alone is not going to stop this spread.

Two is that I've picked about ten books in the library on AIDS and HIV and I read them, particularly the behavioral aspects of them, and each of them take two different approaches. One is that we must stop "promiscuity" and we must "stop our children from having sex and killing themselves." The other message is that we have to stop kids from being homosexual.

Any efforts that are negatively oriented towards homosexuality, in other words to teach children not to be homosexual, will have the opposite approach. Those individuals who are moving towards homosexuality will feel more and more guilt about their behavior and therefore will be out of control. Therefore, the intelligent approach is to begin to neutralize the homophobia of our culture and at the same time to begin to emphasize monogamous committed relationships. There are many propaganda campaigns that could be used very effectively to emphasize the importance of monogamy in committed relationships. And that's desperately needed.

I think what we need to do is rethink our idea of safe sex, and particularly, which has been mentioned previously, which give people the illusion that they can go out and continue their hypersexual activity as long as they practice safe sex episodes. Because what people will do is use the illusion of safe sex as part of their rationalization and denial systems and kill themselves and other people.

Finally, as has been said this morning, I strongly emphasize the early intervention techniques. All of our knowledge shows that the earlier we intervene with compulsive sexual behavior, the more effective we are and that most of these individuals who get involved with compulsive sexual activity

begin during the adolescent year and early teens. The programs that have been oriented in those directions have been the most effective ones. Thank you.

COMMISSIONER CRENSHAW: Thank you, Doctor Schwartz.

COMMISSIONER CRENSHAW: Doctor Earle?

DOCTOR EARLE: Madam Chair and distinguished members of the Commission, I'm Doctor Ralph Earle from Scottsdale, Arizona. I'm a psychologist, past President of Arizona American Association of Sex Educators, Counselors and Therapists and presently present-elect of the American Association for Marriage and Family Therapy.

I'm honored to have this opportunity on behalf of the American Association for Marriage and Family Therapy to present testimony to look at the implications of the AIDS epidemic for the family and for society, and in particular, the role of marriage and family therapists in AIDS prevention and education.

I believe you already have a copy of the written testimony and what I will, as well as several of members of the panel, do to prevent repetition -- is to talk about some of the highlights from that.

I feel strongly that the prevention and treatment of AIDS must be approached with intelligence, a frank talk and a minimum of moral judgment. And most of all, that it be done with compassion for the people involved. The loss of each person with AIDS diminishes each of us as members of the human family.

AIDS prevention begins with education directed at behavioral change. Marriage and family therapists, like most other health and professional --mental health professionals, have regular contact with many different individuals, couples and families. Not only must we have efforts at outreach and prevention and education, but we do need to target these to identify high risk groups, including gay men, IV drug users, adolescents and those who are sexual compulsive or sexually addicted, as Doctor Schwartz has been talking about. I agree very strongly with his emphases in dealing with that area and target population.

But it's also important that every effort be made to keep low risk groups, individuals who do not engage in high risk activities and who are in long term monogamous relationships to keep these people at low risk. It is not uncommon in my practice, I assume it is with other people at this table, for couples experiencing marital distress who five years ago might have separated and not really worked on their relationship and perhaps have gotten divorced to enter therapy with a very firm

and genuine commitment to work through and resolve their difficulties. I've seen this as a shift in the last five years about couple's perceptions about permanence of relationships. It is conceivably that at least to some degree this shift is driven by a fear or anxiety about AIDS.

As a marriage and family therapist who frequently practices sex therapy, I often tell my patients who wish to remain monogamous and enrich their relationship, that monogamy does not have to mean monotony. I appreciate Doctor Kaplan's talking about that area in terms of the fact that a monogamous relationship can involve passion.

Part of our responsibility is to teach people as to what this can mean and to help to increase options and to enrich lives of people who already have a relationship going. This message, obviously, is not applicable to every couple or for every relationship. Nonetheless, for those couples who do choose and are personally committed to maintaining and enhancing their relationship, marriage and family therapy can help them to obtain this goal.

A consequence intended, or perhaps unintended, is that a monogamous relationship between non-seropositive individuals facilitates the maintenance of their status regarding sero-positivity. This principle of AIDS prevention is true for couples both in heterosexual and in homosexual relationships. Intervening systemically to enhance and strengthen relationships can be viewed as prevention of HIV infection. And currently, however, marriage and family therapists must instruct these couples and other couples in safe sex practices. Again, I was impressed by a definition by earlier panelists in terms of what safe sex practices mean.

It's also crucial that other individuals who choose more high risk oriented behaviors be counseled regarding high risk safe sex practices. This is especially important. As Doctor Schwartz was just talking about, the younger population in dealing with adolescents.

We must make certain that our educational efforts in AIDS prevention initiatives are implemented with appropriate sensitivity for cultural issues, for ethnic issues, for religious issues, for values which differ among people and also for different sexual orientations.

An integrated approach to health and mental health care with the family system approach looking systemically at who the family members are surrounding this person as a central conceptual model can give the PWA the physical and emotional support and strength to retain the will to live and moreover, to continue to live a fulfilling life.

First and foremost, I think, the seropositive individual must be counseled to change his or her sexual behavior. It is imperative that the marriage and family therapist, psychologist, psychiatrist, social worker, whatever the orientation of the person is, realize that this is a part of the role to mandate counseling on the maintenance of a monogamous relationship as a viable option. The individual must also receive strong encouragement to advise his or her spouse or sexual partner about the diagnoses.

As you have already heard, health and mental health practitioners are grappling with whether or not they personally have a duty to warn the spouse or sexual partners of a HIV infected person. It's a very difficult and yet compelling issue that we as health professionals are coming to grips with and have to come to grips with. Obviously the professional's ethical responsibility to protect the partner must be balanced by the responsibility to respect the client's confidentiality. This issue may be even more complicated in the case of marriage and family therapy where the "client" in a therapeutic relationship may be more than one person. It may be the couple or can be the family as a unit.

Marriage and family therapists can help individuals, couples and families to make sexual choices and other lifestyle alternations according to their value systems. In fact, I believe it is the role of the marriage and family therapists to look at values, to deal with lifestyle options. The marriage and family therapist does not dictate morality. However, it is our responsibility to educate clients about risks and to help them to deal with the anxieties which may be propelling them into behaviors that they feel they cannot -- and fear they cannot control or manage. The kind of person, for example, that Doctor Schwartz is talking about in compulsive sexual behavior.

I've discussed the emotional devastation experienced by the persons with AIDS. AIDS doesn't just happen, though, to an individual. It has a severe and lasting impact on the family as well given the high incidence of HIV infection in the gay population and among intravenous drug users. The definition of family must include all of those who have a significant relationship with a PWA. It is our view that the family can be defined as the family of function. And this will differ from one person to another.

It is crucial in my judgment that the health and the health care and treatment of PWAs throughout the course of their illness be viewed in the context of the family system. I believe that voluntary counseling and testing should be available for all who request it. Strict confidentiality and anti-discrimination protection are essential in this area.

Marriage and family therapists have been and are active as important participants in the treatment of AIDS. The common thread of the work of marriage and family therapists with PWAs and their families is their emphasis on the family in every case and their use of a family systems model as a conceptual framework. Marriage and family therapists help the person with AIDS and their partner or family to try to balance hope with realism.

On behalf of the American Association for Marriage and Family Therapy, I'm pleased to provide the following recommendations:

First, that AIDS prevention and education is and must remain a priority issue.

Second, that the dual focus of AIDS prevention and education activities should be both to minimize the risk of becoming HIV positive and to prevent the further spread of the disease through high risk activities.

Further, it is recommended that a family systems model become an important value and applied conceptual approach for the design of such initiatives. That we think systemically as we design treatment modalities and look at prevention.

Third, the importance of marriage and family therapists must be recognized and affirmed in the effort to curtail the spread of the HIV virus and provide appropriate and necessary treatment.

Fourth, the funding for appropriate and necessary AIDS related services must be readily available through both government sponsored and private sector programs.

And fifth, the public and private sectors must fund the development of and make readily available opportunities to train marriage and family therapists and other mental health professionals to become proficient in disseminating accurate and timely AIDS related information and to implement effective interventions both to prevent the spread of HIV virus and to provide appropriate treatment to infected individuals and their families.

Sixth, the work of this Commission and other related initiatives in both the public and private sectors must support biomedical and psychosocial behavior research that Doctor Judd mentioned in the testimony earlier, as well as program development and implementation designed for accurate answers and effective interventions regarding AIDS and other related diseases.

Seventh, the federal government must provide leadership to our nation in reviewing all the relevant information about AIDS and related issues, facilitate education and combine hope with realism as solutions are sought for this challenging and tragic public health crisis. Most of all, the tragedy of AIDS must be viewed in human terms. Again, with compassion.

In closing my remarks I strongly support the Commission's efforts to address these issues in a progressive and compassionate manner. However, much remains to be done. The AIDS epidemic should be viewed for what it is, a frightening, tragic illness which we must make every effort to prevent through education and behavioral change. We are well equipped to treat and unable as yet to cure this deadly disease. The American Association for Marriage and Family Therapy is prepared to help our nation meet the many challenges that I have outlined for you today. I thank you for this opportunity to provide testimony and look forward to our continued work together.

COMMISSIONER CRENSHAW: Thank you very much.

COMMISSIONER CRENSHAW: I'd like to address the first question to Doctor Judd because you, in a way, are a prerequisite to the concepts involved in the presentations of the remaining panel members. You mentioned issues that are critical to understand pertaining to behavior change. One is the use of recreational drugs or alcohol even short of IV substance abuse that will impair a judgment and certainly impair the effectiveness of any behavior intervention that occurs. And the other was the central nervous system questions that exist.

Starting with the second, we've heard from--we've heard almost uniformly from witnesses that the central nervous system impairment is important in the clinical syndrome of AIDS and significant there, but not of concern at this point in time for policy decision making in the asymptomatic HIV positive. Would you comment on that and --

DOCTOR JUDD: Yes. First of all, this is still an open empirical question that needs an empirical answer. Right now we have evidence from one independent study and from an analysis of a cohort study that we're sponsoring, in which investigators were looking at whether or not seropositivity leads to changes with regard to cognitive processes. Both of these highly preliminary, but intriguing studies have presented rather interesting leads indicating the answer was yes. In one which involved only a small number of patients, there was a two standard deviation increase in the measurement of cognitive disordering in individuals who were seropositive but as yet asymptomatic.

We feel this issue is sufficiently important that right now we are putting in place a number of studies to look at a much broader group of patients, to track them from seronegatives to seropositive status, and through the whole ARC spectrum. And, in fact, as I indicated, we have a conference that's on going today that also addresses this issue. We gathered together most of the major experts in cognitive and neuropsychology in this country, one, to review and assess the data that we have currently, and secondly, to see if they can agree upon a standardized neuropsychological cognitive psychology battery with which to measure this in a broad spectrum of patients. Thirdly, the participants, hope to begin to determine which abnormalities on neuropsychological testing mean in terms of everyday functioning.

Right now, we feel that there is no answer on this. The question is of enormous public health importance and is certainly highly germane to our institute. We feel it's very important that we develop data quickly upon which to base public policy. It would be very premature to come down on one side or the other before the information is available. All we have now is rather frightening, alarming preliminary information indicating that in two small groups of seropositive individuals, demonstrable quantitative abnormalities in thinking were present.

COMMISSIONER CRENSHAW: I'm under the understanding that compared to other people there's enough dysfunctional people in the normal population that there's no difference between -- at least this is what has been shared with us -- that there's no difference between the extent of involvement in HIV asymtomatics and the general population and perhaps the Commission here today.

DOCTOR JUDD: Right. Okay. I can't attest to the latter. You seem very alert and very sharp, so let me just give you the data, that is currently available on this.

We looked at some neuropsychological testing data obtained from in a cohort that was being followed for another purpose. There was a ten percent prevalence rate of demonstrable abnormality in the seronegative individuals. Once they converted to seropositivity, that doubled to 20 percent. So, there is some evidence of cognitive disordering linked to sero-status.

In his comparison study, Igor Grant, a neuropsychologist in my former department at the University of California, San Diego, looked at four groups of individuals: One with full blown AIDS, one with ARC, one with seropositivity but asymptomatic, and the last seronegative. All matched well on the basis of exposure to alcohol, drugs, age, educational status, et cetera. They were, rather well balanced in that regard.

Of the individuals with full blown AIDS, 87 percent demonstrated serious cognitive disfunction. Fifty-four percent of individuals with ARC had neuropsychological abnormalities. What was quite surprising, was the funding that 44 percent of individuals who were seropositive but asymptomatic had the same kind of neuropsychological abnormalities against a base rate in the seronegatives of nine percent.

So, in two studies in which the only intervening variable was conversion to seropositivity but with no other symptoms evident, in one case neuropsychological abnormalities it doubled; in other case it was four times what it was. We feel that that's indicative and sufficiently alarming that we bring immediate scientific information to bear with regard to this and then provide it to people like yourself and the federal policy makers to make a decision as to what is done with the research evidence. But it is an open issue. It's still an empirical question. It is waiting to be answered and we are ready to begin answering it.

COMMISSIONER CRENSHAW: Thank you for clarifying that. And I'll tell you this panel comes at a very opportune time because we've just recently over the lunch hour visited with a woman who was married for, I believe, 37 years to a man and he had AIDS, she became infected. She wasn't told for 11 months and found out by confronting her physician. So there was no duty to warn in place. And this was a man she knew for such a long time and didn't have a clue that there was compulsive sexual activity of a homosexual nature going on throughout the course of their marriage, or for the majority of it.

So I would like to turn the questions over to Kristine Gebbie at this point.

COMMISSIONER GEBBIE: Thank you.

And my apologies to the panel for not hearing your oral statements. I got caught up with doing some things back there.

I guess I'm going to start with just asking for a clarification on what you just said, Doctor Judd. This whole issue of the neuropsychiatric symptomatology is one we've talked about several times.

And the last witness we had speaking about it, somebody might think was very knowledgeable, was very crisp to differentiate findings of more positive test results on specific test skills, doing psychomotor tests or performing certain tasks, being higher. And that being something on which you could base a conclusion such as limiting the person's activity in the world of work.

Having heard that testimony and now hearing you use the word "alarming," my sense is that it was alarming in the sense that it makes research people sit up and take notice and say we'd better pursue it further as opposed to alarming meaning my goodness we'd better go change whole policies out there in the external world. Would you clarify which use of the

word --

DOCTOR JUDD: I agree that it would be highly premature to change policy one way or the other at present. We do not have the necessary information. It is concerning -- it was a surprising finding. Nobody anticipated it. In a sense, the HIV infection, of the brain has been a little bit of a late comer in terms of our awareness; it was only in 1987 that dementia became part of the AIDS syndrome. At that point, people began to question when it starts. Most often it occurs rather late in the AID's syndrome. On the other hand, these groups began to look for it earlier and, surprisingly enough, found that there was evidence, of deficits prior to the time that any other symptomatology was present. At that point we felt that it was incumbent upon us to develop substantive information in that regard because it was a potential policy and health issue.

COMMISSIONER GEBBIE: Thank you. I just didn't want people to think you were changing what we had heard.

My next question is for you and it deals with some clarification of the role of ADAMHA and the NIMH. In the more physical health areas I'm used to working with two distinct arms, one of which is a research arm generally looked at at the NIH and there is a more activist community arm, the CDC. And while they have overlapping missions, you kind of see a distinction. Within areas pertinent to mental emotional behavioral problems we tend to see this one box. And at least from the outside it looks at lot as if that box is much more concerned about the academic and research pursuits and is not so clearly engaged in demonstration projects and an aggressive service arm that might be out there. And so when people in public health practice wanting to figure out to what to do on the behavioral side look for who their federal partners should be, we don't quite see it the way we do on the physical health side. Could you clarify that?

DOCTOR JUDD: I'll attempt to do that. First of all, the NIMH is one of three scientific institutes within the Alcohol, Drug Abuse and Mental Health Administration. Our primary mission, at least at the NIMH, is the conduct and sponsoring of scientific inquiry into the etiology and development of treatments for mental disorders. That is our primary mission.

In addition, we have other responsibilities or missions -- e.g., in regard to training mental health care providers, we have a small but very active and I think creative program. We also have a demonstration authority under which we implement research-based service demonstrations. That is, we look at and assess novel ways to approach various populations; if they prove effective, we publicize that, you know, for the remainder of the mental health system to use.

Prior to 1981, the NIMH did have a stronger direct service orientation. With the Omnibus Reconciliation Budget Act of 1981 the clinical service programs of the institute were put into a block grant mechanism and moved out of the institute -- currently, they're housed in ADAMHA and are not a part of the NIMH operation although we do provide technical assistance in the monitoring of the block grant. But that's a pass through, with money going to the States on a formula basis.

So essentially, our major mission, is one of a scientific nature to be the research and development arm of the government in providing better understanding of mental disorders, how to diagnose them better, and how to treat them much, much more effectively.

At the same time, we do have small demonstration programs. These are an extension of our behavioral change research efforts. We see ourselves as the institute with the expertise in this area. We are developing what we hope are strong research-based models for intervention that other components of the government might take on -- components which have much broader experience in the large community intervention which we essentially have not been involved in over the last decade.

I don't know if that clarifies.

COMMISSIONER GEBBIE: This clarifies some of my questions. It leaves me with another twist on the question.

DOCTOR JUDD: Yes.

COMMISSIONER GEBBIE: I mean we're here not just to hear what is, but to consider what might be or what should be. In your prospective, given what's going on, research needs, but also very clearly service needs and a need to be able to respond swiftly with building up service models or different kinds of service, is that present balance with what's clearly the research mission dominating in this weaker and more centralized, it sounds like, service arm appropriate or we be looking at that. Is it meeting the needs of the community and perhaps other people who've tried to work with the system on this panel would have comments on that as well.

DOCTOR JUDD: I can only indicate that the balance seems about right to us at this point. The monies that flow through the NIMH currently represent 92 percent of the entire research effort in mental disorders in this country today. We are, even with our block grant, a tiny drop in the bucket for mental health services for the United States. And so erosion into that rather precious commodity in which we represent virtually all there is in terms of advancing the fields understanding mental disorders and developing new ways to respond to it could have severe ramifications, I think that one would have to look at that very carefully and to see whether or not it would be a responsible position to take.

COMMISSIONER GEBBIE: I'm pushing it just a little further. Your right that the bulk of the money, at least as I understand it, for mental health services is state and local money that, I think, is tied up heavily with -- or it's private money in private treatment resources --

DOCTOR JUDD: No. In actuality the federal government is a very small player right now with regard to mental health services in the country. A decision was made in the past to develop a pluralistic community-based mental health system for this country that is designed on the basis of the needs of each individual community and/or State. And so, over time, the States basically have taken over a significant component, at least of the public mental health sector. The third party payers, you know, certainly cover the private sector. So the NIMH is really a relatively small player in the public mental health game in this country.

COMMISSIONER GEBBIE: My impression may be wrong because I haven't looked at number tables recently, is a whole lot of those resources are tied up in institutionalized populations, in chronically mentally ill populations, in some very traditional approaches, and, therefore, my push on where is the federal service arm is tied up with where do we have some flexibility to move quickly with new models of treatment, or with treatment for new populations that might never have been contemplated when things earlier got locked in.

And, you're not raising that as a problem, at least as you have seen it.

DOCTOR JUDD: Not at this point. I think that you would have to ask the States, in a sense, because I can't speak for them, as to whether or not they have flexibility with regard to moving in new areas of high need.

You know, while the States would have to answer to you in this regard, I think to characterize the contemporary public

system as primarily "traditional" would not be fair. There are a number of very imaginative and innovative community-based programs in this country that are rather flexible and are not tied up with the so-called "classical state hospital system."

COMMISSIONER GEBBIE: Okay. My other question is addressed broadly to the other four people, and if you answered this in your formal presentations, my apologies, just tell me what page to read it on and I'll go read it.

It's not clear to me from what we've heard so far in this area that folks who are on the front line in caring for people with behavioral manifestations of this disease, or with problems associated with the sexual behavior, are an integral part in designing the research studies and the programs that need to go forward. We hear about behavioral science research that needs to happen, but I, at least, have heard it more from people who are academically oriented, or theoretically oriented, as opposed to folks that are out there on the front line.

Is that an accurate perception? If it is, what ought we be doing to make certain that we have some better integration of that front-line experience with what is being designed in the research setting?

Doctor Kaplan is jumping up and down.

DOCTOR KAPLAN: This is my written recommendations, although it did not mention this in my oral testimony. My first recommendation is, that a committee, be-formed, hopefully federal sponsored, composed of infectious disease experts, public health professionals, sex therapists, other mental health professionals, etc. to develop guidelines for therapists for advising their patients. Because, currently we have heterogeneous group of education programs, and counseling policies. Many are doing more harm than good, by exaggerating the safety provided by condoms and the hazards of testing and by sometimes giving other kinds of misinformation. We need a unified guideline, developed by experts such as are gathered here today, if we hope to change the public's risky sexual behavior.

And, my second recommendation is that symposium workshops be held at the American Psychiatric Association, the American Psychological Association, and at other relevant specialty meetings specialty meetings. I think such HIV education programs should become part of the licensing or re-licensing requirements, to insure that professionals really attend these workshops. But, before you give a workshop, and before you give advice, you really have to have a consensus of experts from various aspects of the field. This has sadly been lacking.

You give money for education. They tell the kids, go use condoms, and don't take the test -- which is terrible advice. We need consistent guidelines. Education can do more harm than good if it is politically motivated instead of based on health consideration.

COMMISSIONER GEBBIE: Any other comments on that question?

DOCTOR EARLE: I agree with Doctor Kaplan. I think that it make sense for some of the mental health professional associations, or all of them, to work together in that area. I believe their research committees, or task forces, or boards in these various groups that involve people not only from the academic world, but people who are in practice, and the AIDS area is being looked at, but I think working with NIMH and as associations we need to do more.

DOCTOR JUDD: If I might just respond to that briefly to let you know what is ongoing in that particular area.

One component of the NIMH AIDS portfolio that I did not mention is an educational effort that was initiated two years ago, in which we let 21 contracts to 21 different institutions to permit them to become centers for educating health care and mental health care professionals, (1) the facts about AIDS, (2) how to approach it in clinical setting, and (3) how to develop a consistent message in terms of counseling individuals.

We now have underway a parallel evaluation of that training effort. The data is not completely in, but I've seen it recently, and I would say that it looks rather good. There has been a marked change from baseline to second testing in regard to availability of accurate information, comfort in dealing with this particular population, and dispelling a number of the mystiques, fears and clinical myths that persisted with regard to AIDS patients.

COMMISSIONER GEBBIE: That sounds more like what you are putting out, not what you are opening up your research to them putting in to you on what needs to be done in the research.

DOCTOR JUDD: I thought I was responding --

COMMISSIONER GEBBIE: It's going both ways.

DOCTOR JUDD: -- to the, you know, amplifying the other witness' answers.

DOCTOR SCHWARTZ: May I make one more statement about that. I think what you said is an accurate statement. I think the quality of research in the behavioral end among clinicians in

the front end is uniformly poor. I think the number of people doing research is far too few.

I'm the head of -- there's a conference coming up on sexual compulsivity, and I just went through all the papers that are being given on sexual compulsivity from around the country. The number of research papers is very few.

The reason for that is unknown, except for the fact that the interest in AIDS came historically after a long time of individuals not getting funded in the area of sexuality. It was not a high-priority area, and so a lot of the quality of sex research in this area, I think, began to decrease. It's now, we're seeing a change, and it's increasing, as with increased funding.

DOCTOR JUDD: I might try also to respond specifically to your first question, and that was, are the people in trenches getting together with those who are conducting the research.

I would say that one of the better models that we have developed along this line involves the three AIDS centers that the Institute is supporting, in New York, Miami and San Francisco. Each pulls together a consortium at multiple institutions, where, a significant number of HIV-positive individuals showing up and being taken care of, and get front-line clinicians together with academic researchers. Out of that amalgam has come a number of the research questions that they are addressing.

It is a beginning, but this has traditionally been a problem in medicine -- that often times, patients who are responsible for every-day care of individuals are not those individuals who are formulating research questions or conducting the research. I think it's a very good point that we have to bring researchers and clinicians together to help make more precise the research questions being asked, and to design more effective studies.

CHAIRMAN CRENSHAW: Admiral Watkins?

CHAIRMAN WATKINS: Doctor Judd, we've been surprised at times to look at such mundane things as budget lines and trends. I'd like very much to have the NIMH budget line for the past five years and the projected years. What's going into NIMH within your organization, where I know you parse out dollars in a variety of ways, but I'd like to know what our past actual expenditures were in constant dollars, where you are going? And then, I'd like to see the differential that is imposed on that line by the AIDS epidemic, and I'd like to also see it in terms of full-time equivalence applied.

We get the feeling on the Commission that this is an area that's been, frankly, ignored, I mean in terms of the larger set of issues. We're not convinced that the human resources assigned to mental health across the nation are adequate to meet this kind of epidemic, where this becomes a very critical resource issue. We had a presentation yesterday from a lovely lady, Doctor Burgess, who is a psychiatric mental health nurse at a very high level of skill. There are a handful of her in the nation.

Are we prepared, do we have the incentive programs to move a variety of people at different levels and skills into this region, and what is the role that NIMH plays in that?

I have to run, and this is -- I'm asking you a lot of questions, but I really would like to have a much more definitive budget layout.

When we've seen some of these, we've been appalled at the lack of responsiveness of the budget line to the needs, and we recognize that's not your role all the time to move around, but we have a memorandum here from the American Psychological Association, right or wrong, that is very concerned that you are going to be robbing Peter to pay neuroscience, Paul, from behavior research to the other.

Now, that may or may not be valid, but there is a perception out there that we're trying to do all the things we need to do for AIDS within the same budget line, which are already declining and may well be in your area totally inadequate for dealing with this epidemic.

Can you give me some general answers, and then we'll get some specifics?

DOCTOR JUDD: I'd be glad to provide that information for the record. I do have some of the highlights of it.

Let me take the last question first, that we are robbing Peter to pay Paul. This is, in my view, completely inaccurate.

Currently, with regard to our AIDS portfolio, as I indicated approximately 62 percent of our research effort is devoted to attitude behavioral change and to studies of psychosocial factors associated with of AIDS. 10 percent of our budget is being devoted to neuroscience at this point.

There are those who are criticizing us for that as well, feeling that given the issues with regard to AIDS dementia that are so germane at this point, that we ought to be beefing up that side of it.

So, I'd say that criticism of our level of investment in behavioral research misguided and, I think, poorly informed.

Secondly, you have to understand that our AIDS budget follows from a separate federal source an is accounted for separately from general mental health research funds. That is, our NIMH budget is created independently from and accounted for separately from the AIDS budget. So, there are no tradeoffs gong back and forth between the two budgets.

AIDS funds are being very carefully monitored throughout our department and down through ADAMHA to the Institute. We account for every nickel that goes into AIDS, to ensure that it is spent in ways that are highly germane, relevant and important to that effort.

To give you an idea of the growth of our budget in this regard, in 1987 it was $13 million, in 1988 it is $30 million, and in 1989 it is projected to be $49 million. So, we have had a rapid increase in our NIMH budget with regard to AIDS.

With respect to another question that you raised, "at this point, are we doing enough?" We have some concerns at this point that, not only is not the clinical component of the field not ready to mount a major effort in this regard, but we're concerned about the scientific component of the field as well.

The only thing that brings us some comfort in this regard is that we are not creating a field out of whole cloth -- It is multi-disciplinary research, and we are bringing people who are already trained in very specific scientific areas to bear on the AIDS problem. We believe that we will be able to fund high quality research, even though there has been a rather steep increment in our budget to this point.

CHAIRMAN CRENSHAW: If I can interject here. Correct me if I'm wrong, but it's my understanding that the American Psychological Association recently received a three quarter million dollar grant from NIMH. Am I correct?

DOCTOR JUDD: I'm not sure of the project to which you are referring. We have one program with -- and, it's actually in a minority area -- for the training, basically, of neuroscientists, and recruitment of minority neuroscientists into training. I'll have to get that information.

CHAIRMAN CRENSHAW: I will check on this, but it was my understanding that the AIDS Task Force of the American Psychological Association recently was heavily funded by NIMH. It might be another government.

DOCTOR JUDD: Well, you know, it's conceivable. I don't know everything in our budget at this point. I'm new to the directorship. I thought I knew everything. That one I'll have to check on and I'll get back to you. Thank you.

CHAIRMAN WATKINS: We would like to see the budget breakout and the change with the AIDS epidemic, and also like to see the full-time equivalent, and then I'd like to know whether that's adequate. It's hard for me to know 62 percent of what, 62 percent of an inadequate number is an inadequate number. If it's an adequate number, then are you saying you have all the funding you need to do what the nation has to do in this area of mental health, and is that the same view held by the outsiders who look in, because we get a different view from other places.

Not that you aren't doing your job and minding your store, that's not the issue at all. The issue is, is it ramping up at the same rate consistent with the other resources devoted to the AIDS epidemic in the country?

DOCTOR JUDD: I don't have full information on the increase in the other areas. The NIMH entered relatively recently into the AIDS research area, but that's the one part of our budget that is increasing, far more rapidly than any other part. Essentially, the Administration budget for this year is a continuing services, hold-the-line budget, except for AIDS, and we are getting a $20 million increase in AIDS, up to almost $50 million.

So, the issue really is, to make sure that the money is well spent --

CHAIRMAN WATKINS: Exactly.

DOCTOR JUDD: -- for high-quality research. The one thing that I feel my job is in the Institute is to ensure that the taxpayer's money is well spent, that the research is, one, expended in meaningful public health areas; two, that expenditures reflects congressional and constituent interest, and, thirdly, that we support the highest quality research possible.

CHAIRMAN WATKINS: But, do you agree with Doctor Kaplan, that at this point in time, for this epidemic, we should involve the collaborative decision-making of a lot of people that are working the problems in the field. Maybe something unusual at the outset to provide the kind of guidance that you might need to ensure that the dollars are being placed where everyone at the various levels, including those at grass roots, feel comfortable. They understand what's going on in the mental health area, as it relates to the HIV epidemic, and that they are, perhaps, players that can help steer this effort.

DOCTOR JUDD: Just to assure you along that line -- and, again, it may not be as representative as you would like --, we have an Extramural Science Advisory Board that functions in the Institute that has regularly looked at the AIDS portfolio and made a number of suggestions, which we have been highly responsive to.

In addition to that, the Institute has in place the National Mental Health Advisory Council, which met just yesterday. That council serves as an advisory to the Director and provides an oversight function for our scientific portfolio. The AIDS portfolio was reviewed yesterday.

In addition to that --

CHAIRMAN WATKINS: Has that been enhanced at all, the membership specifically focused on AIDS, perhaps, with unique ethnic representation and the like?

DOCTOR JUDD: We have created a subcommittee of the Mental Health Advisory Council, made up of 16 representative scientists and individuals from various groups, to serve in a policy, advisory capacity to the Council and to the Director, vis-à-vis the shaping of the AIDS agenda.

In addition to that, ADAMHA is about to create an oversight advisory board as well.

CHAIRMAN WATKINS: Will that include community-based organization representation of some kind?

DOCTOR JUDD: It does indeed. In fact, on the Mental Health Advisory Council, there is representation of all core mental health disciplines, plus other constituents.

CHAIRMAN WATKINS: Doctor Kaplan and Doctor Schwartz, do you think that the epidemiological data breakout right now, regarding bisexual males, is adequate?

You are telling us something today, really, it's the first time that it's really come out, in my opinion, quite the way you've presented it, and I think it's very revealing, and I'm just wondering if we aren't disguising an area by the way we breakout male homosexual/bisexual, and then, male homosexual/bisexual and IV-drug abusers, and we let that float by. And, from just the anecdotal information we receive, I'm very concerned that we don't know where we stand on bisexual males in the nation, and I just don't understand whether or not we can -- whether there is something in the epidemiological data base that can be modified to better clarify and breakout this set of issues, because one is clearly applicable, as you point out in

your statements, into the potential heterosexual spread problem. And so, it seems to me that, perhaps, needs to be cleaned up at some point with the proper research or to identifying how you would do that.

Could you comment on that briefly?

DOCTOR KAPLAN: It has been well known since Kinseys' 1948 survey that there are far more heterosexually active bisexuals than there are exclusive homosexuals. But, that is a very difficult area, as Doctor Schwartz said. Bisexual men can not as a group be expected to be open since they often try to conceal their sexual behavior.

I think we do need much more information about bisexual behavior because this is the greatest hidden danger for the middleclass woman. For the minority woman, sexual transmission by an HIV carrying drug male abuser is the major danger, but the bisexual male is the hidden source of HIV infection for the majority of American women. Some scientists have started to do some pilot work with bisexuals who are unable to have relationships with women because they are blocked in the heterosexual aspect of their functioning.

And, when you work with that, rather than doing anything negative about the homosexual side --

CHAIRMAN WATKINS: Have you given us a recommendation along those lines?

DOCTOR KAPLAN: I will prepare one.

CHAIRMAN WATKINS: I'd like to get your opinion on that too, Doctor Schwartz. What should we do in our recommendations to flush this area out, perhaps, either in research or other ways, to try to look at it in greater depth and try to begin to understand it?

DOCTOR SCHWARTZ: I think that you are raising a good point. I think that one of the major reservoirs that is going to move AIDS from the homosexual community to the heterosexual community certainly is going to be the bisexual individual.

The other big reservoir is going to be the prostitutes. I didn't talk about it, but we have a large number of clientele who frequent prostitutes of the same gender.

To focus on those two individual groups, as a high-risk group, the only way to focus any kind of educational efforts is going to be focus on the broad heterosexual community, because you can't count them, so to speak.

The interesting thing is, is that the way I've got large numbers of people to come in has been through media. When the media finds out that there is a program available to help these individuals stop, there is large numbers of people that want to come in, as long as it can be anonymous. I think a large number of these people want to stop, but they don't know exactly how to go about it.

Also, we said that the number of therapists that have been trained in this are very few, because all the old ethos that Doctor Kaplan and I, we used to be together and talk about, was the old ethos in the profession was that, if you are bisexual then you really "are a homosexual, but you are just sort of faking it." And so, the old ethos was, you help bisexuals to learn how to be homosexual and move into the homosexual community.

And, what we have been working on for years is the realization that many bisexuals can make it just fine in heterosexual relationships, not all, but some, and we've been fairly successful in helping bisexuals who want to move into a heterosexual relationship do so successfully.

I think the work that we've been doing is not commonly done among clinicians.

CHAIRMAN WATKINS: I appreciate your bringing this to our attention, and I would like to see, Doctor Kaplan, your recommendation.

Thank you very much.

DOCTOR JUDD: I wonder if I might add something to that. You made a request in regard to a data base. You know, there is, in process right now, a rather large planned survey of sexual behavior that is going to be initiated by the National Institute of Child Health and Human Development. A number of the other institutes, including our's, will be participants in this.

This research survey will examine contemporary sexual behavior, and, if people ar straightforward and honest in responding to the survey, will yield information regarding patterns of bisexuality.

CHAIRMAN CRENSHAW: What I would like to ask is an open --

COMMISSIONER PRIMM: Doctor Crenshaw?

CHAIRMAN CRENSHAW: Oh, I'm sorry.

COMMISSIONER PRIMM: That's all right.

CHAIRMAN CRENSHAW: Yes, please, Doctor Primm.

COMMISSIONER PRIMM: Thank you. I thought I was going to get passed over there for a minute.

CHAIRMAN CRENSHAW: I didn't see you return.

COMMISSIONER PRIMM: I would certainly like to say to Doctor Kaplan that there is a great fear, and it's my own personal experience that there are a number of minority, particularly, black bisexual males, who never come out of the closet, who masquerade as heterosexuals, I think we have the fear that is maybe not as great for that group as it is for intravenous drug users who have sexual partners and transmit the virus that way, but we have a number of bisexual males that never come out of the closet because we don't have support mechanisms for them.

If you are white and you are bisexual, or you are white and you are homosexual, you can come out of the closet, and there is the Gay Men's Health Crisis, there is all the gay organized organizations, but for blacks they are few and far between, so they remain in the closet and it's a big danger.

So, I would like to suggest to you to look at that group also as a very dangerous threat to the other communities.

DOCTOR KAPLAN: I couldn't agree with you more, and many people, myself included, have the feeling that it was the bisexual minority male who first was the bridge for the virus to the minority population from the gay community. And, the same thing could happen to the general population. I think you are quite correct.

COMMISSIONER PRIMM: I think another source is overlooked. We have many males who go to prison, and who are neither bisexual nor homosexual, and end up, in order to survive, having a homosexual relationship in prison, and then come out of prison and, return to their heterosexual state.

I'm concerned about another issue that you could help me with, Doctor Kaplan, and certainly, Doctor Goedert; that of using spermicide, and, particularly, the use of spermicide by women. We often talk about the use of condoms, et cetera, as a way to possibly have safer sex practices, which I'm not so sure is the utopian thing to do. First of all, in any other deadly disease that could be transmitted, I'm wondering, wouldn't we say abstinence is probably the thing to do, if you are infected that you should not have sexual relationships with someone that you could possibly pass the virus on to. You should have only sexual relationships with someone who is already infected.

I mean, this is a deadly disease, and medically it probably would be sound, given that kind of advice, instead of what we are really saying here, and I know it's impossible to do the utopian thing, but what do you feel about recommendations of the use of spermicide by women, particularly, women whose significant other will not use a condom, or considers that as an insult when there are significant others asked to use a condom that might result in abuse of the woman, et cetera?

DOCTOR KAPLAN: I don't know enough about the actual effectiveness of spermicide, and I would like Doctor Goedert to comment on that, condoms are like filtered cigarettes. It is better to stop smoking but people who can't stop smoking, are better off using filters than nothing. Similarly, the level of protection against the sexual transmission of HIV is not now, but condoms do reduce the risks. Therefore, if woman is really in the position where she cannot avoid sex with a man who may be infected, certainly condoms are better than nothing. There has not been enough research on the possible irritating effects, or the tetragenic effects, or the side effects of the spermicide. Researchers have begun just to study spermicide. We need to know what the risk factors are.

But, it is certainly possible and practice to promote risk elimination for the general public. I like Doctor Goedert's strategy of dry sex, unless you know the HIV status of your partner. That doesn't mean no sex, it means what those of my generation, use to do 30, 40 years ago, called "making out." In other words, there are many ways of being intimate, and of sharing sexual pleasure without actually mingling body fluids. This is very explicit type of material, which many of our colleagues are hesitant to talk about. But, that is one of my recommendation in an educational program, including guidance on how people can have sex truly safely, without exposure to infected body fluids, because, again, condoms are not the answer because again the infected cells are not just in the semen, they are in all the body fluids.

But, I really think Doctor Goedert has more scientific information.

DOCTOR GOEDERT: The data on the effectiveness of spermicide is very, very sparse. There are a little more data about the effectiveness of spermicide in preventing other sexually transmitted diseases, and there, by themselves, it looks like they are helpful, but not very helpful in terms of neutralizing chlamydia and other sexually transmitted bacteria or parasites.

The hypothetical example that you raise of a wife who cannot refuse is an exceedingly difficult one. It gets into the

problem of, you know, marital rape, or wife beating, or what have you. I think even certainly with the sparse data that we have and the data that are incomplete, I think it would be very hazardous to recommend that as an effective way to try and prevent transmission of HIV.

COMMISSIONER PRIMM: Well, I don't mean as an effective way, because we are recommending condoms, and we're not so sure about the effectiveness of that method either. But, we're going to have to do something for women to protect themselves if they cannot be protected by the male, specifically, by utilizing a condom. In your written testimony today, we talked about men becoming impotent, just by using a condom, putting it on, thinking about it, they become impotent. What are we going to do in cases of that kind?

I understand quite clearly your point. Yet, suppose the condom breaks and the spermicide gets into the vaginal vault and comes in contact with the vaginal mucosa or the cervix itself. Then, indeed, we have the same problem, don't we? So, we ought to do some studies. NIMH, should be doing studies on the effect of the condom, or pathological effect the spermicide may have on those kinds of tissues in absorption, or whatever the case might be, because certainly it's been recommended to be used.

I have one more question for Doctor Judd, and that is, I'm wondering how your review committees are structured. That is, those review panels that do the studying in the study sections, that look at the possible grants that you might be. Do you have good representation? You talked about community-based organizations being represented at the advisory level for your quality research that you spoke about. What about the review committees, so that we can ensure that some of these grants are getting out to organizations that are minority organizations, that may not have the kind of attractiveness that our ivy-covered towers do?

DOCTOR JUDD: Well, I hope that the latter statement can never be leveled at the NIMH. Our review committees throughout the Institute attempt to get the best people in the field in to review the grants, but we are very, very mindful, of the need -- and we are under very specific instructions, which we're quite comfortable with, and that we think we've been quite creative and good about following -- to bring in individuals from under-represented and under-served populations and minority groups to serve on those committees.

In addition, we have created very recently an AIDS Initial Review Group, which will be focusing specifically on the AIDS area.

But, with regard to the faring of minority research within the Institute, this is something that has been an area of concern of our particular Institute, really, ever since its inception, and I believe our record is among the very best in the federal government in this regard.

Within the last two years, we made an effort to mainstream minority-oriented research into the Institute rather than having it monitored by a single branch as had been the practice previously. We felt that may not have been fair in its own way, and it wasn't necessary any longer.

I'm delighted to indicate to you that the new organization an procedures have worked extremely well. Over the last two years there have been major increases in both minority-relevant research, and minority-conducted research in the Institute. The increase was 26 percent between last year and this, so, it is one that we're conscious of, we're aware of. We can always do better. But, I believe that we are making, indeed, excellent progress in this regard.

COMMISSIONER PRIMM: I want to commend you on your minority research efforts in recruiting. That's one way for us to finally get into the "good old boys network" that we often talk about. I wonder, are you getting any of the "good old girls" in the "good old boys network" too, because that's a concern of this Commission, that they be included, because I think they have been excluded as well as minorities along the way.

DOCTOR JUDD: I would agree with that, and I think that our record is, again, excellent along that line.

COMMISSIONER PRIMM: Thank you very much.

DOCTOR JUDD: Thank you.

COMMISSIONER PRIMM: Thank you, Doctor Crenshaw.

CHAIRMAN CRENSHAW: I would like to ask a question of the panel members, that I think certainly confronts us all rather frequently, and, I'd like to ask each one of you to identify whatever issues you perceive as some of the challenging and unresolved ethical issues that face you with the introduction of the HIV infection. I frequently hear new things come up when I think I've heard it all, and just last week a physician called me, a urologist who does implant surgery, as to papaverine injections, and he's being taken to court for not returning to sexual function a patient that was HIV positive and an alcoholic, and he was worried about participating.

I'd like some of your points of view in response to this, and also, whatever other things, because this is just one of the many complications. And, my question is going toward the direction of, perhaps, a suggestion that there be some interaction among the organizations to deal with the ethical issues in cooperation that are proposed by AIDS, particularly, because right now the two APAs, the American Psychiatric Association and the American Psychological Association, contradict each other on the issue of contact notification. And, this leads to even more dilemmas within the therapeutic community.

So, I'd appreciate some comments, and then we'll have some questions from Doctor SerVaas and our next panel, but I'd appreciate whatever issues have come to your attention, or whatever thoughts you have, and you might want to start with comments. Doctor Schwartz?

DOCTOR SCHWARTZ: I'm the Ethics Chairman of the American Association of Sex Educators, Counselors and Therapists, so we took a sampling of the membership at the last meeting to look at various problems they are having, and we got those back recently and surveyed them. The membership is having numerous problems, because if they belong to several organizations, as you are saying, there are differential criteria placed upon them, some states have different reporting criteria, and it's a bit of a mess.

It seems to me that the best I can get is, is that the psychiatrists are saying that if they are going to err, if they are going to be sued, they'd rather be sued in the direction of protection. And so, it seems that the emphasis is what Doctor Kaplan was saying earlier that the American Psychiatric Association has taken, which is that if we're going to get sued, we'd rather be sued in the direction of protecting another person's life, and that seems to be where the majority of the psychiatrists are going.

The issue is that psychiatry seems to have always been in that area, when there was problem of somebody murdering somebody else, they'd rather err on the side of protection.

The problem is in non-psychiatry medical fields, a lot of people have respected patient confidentiality for a long period of time and have great conflict over this.

The American Association of Sex Educators, Counselors and Therapists have taken the position all along that every member has the responsibility of protection, which is, if they understand that there is somebody else who is at risk, that they are to notify that person, and I think that's the thinking among the majority of people.

There are many, many unusual, unique kind of dilemmas, like the one that you just described, coming up, and I think that as head of the Ethics Committee, the position that I take, simply, is that we have to err in the area of protecting people's lives, and if, like you say, this physician is giving papaverine to somebody who has a positive HIV, he's contributing potentially to another person's death, and that would need to be looked at very seriously.

CHAIRMAN CRENSHAW: Doctor Earle?

DOCTOR EARLE: Doctor Crenshaw, I agree with what Doctor Schwartz just said. One of the things you mentioned that I believe would be very helpful, is to have the ethics groups, or committees, or boards of different associations get together, and to look at this and explore it together, because I think it is confusing. It's confusing to those of us who belong -- I must belong at least to five or six different professional associations, and that makes it tough if ethics codes are quite different, there is a real dilemma for the therapist on the scene. Plus, I would like to believe, do believe, that by getting together we're able to deal with people outside the mental health field in a much more unified way, and get listened to better, and should be listened to more when we get our act together that way.

The American Association for Marriage and Family Therapy Association's Ethics Committee is dealing with this issue of duty to warn. I personally agree again with what was just mentioned by Doctor Schwartz, that the protection of the individuals would be my first challenge, and certainly, trying to deal with confidentiality in an ethical way, but protecting the individual is tantamount, I believe personally, to the therapist.

CHAIRMAN CRENSHAW: Thank you.

DOCTOR KAPLAN: The question is one of which tragedy do you choose over the other? This is a very difficult question. It will be resolved, if ever our social attitudes, the stigma of AIDS is changed, and then it will no longer be so much of an ethical dilemma.

For a physician, the saving of human lives is always the first priority. There simply can be no conflict about that. The choices are a little easier for physicians because of that particular tradition, but it is a terribly difficult question nevertheless. A professional should try to avoid getting into the position of having to face this dilemma. He or she should try to work with the infected patient, and pierce his denial, and attempt to appeal to his conscience, and raise his consciousness, to his responsibility toward his sexual partners

and, hopefully, he himself will disclose his HIV status. This should always be tried first, and the notification should be a court of last resort.

CHAIRMAN CRENSHAW: Thank you.

Doctor SerVaas will have a couple of questions, and then we must wrap up for our next panel.

COMMISSIONER SerVAAS: My questions are for Doctor Judd, and should most sexually active young persons diagnosed with schizophrenia have AIDS ruled out in the differential diagnosis, and is it difficult to differentiate between the dementia of AIDS and schizophrenia or Alzheimer's?

DOCTOR JUDD: Well, let me indicate first of all, I think that this whole area needs a great deal of study and, understanding. I think there is almost no data on sexual behavior and sexual practices of the seriously mentally ill, and especially those who are chronically mentally ill.

It does not appear to be likely that the qualitative components of the potential cognitive disorder that may be seen early on in AIDS would be confused with pervading disorder that occurs in schizophrenia. It would be very hard to mistake the two.

Further, because the presentation of a full-blown dementia in AIDS usually occurs relatively late in the course of the disease, anything that could mimic, organically, the initial presentation of a psychotic disorder I think would be so clear cut that confusing the two would not be an issue.

I do think that we need to get better information regarding the sexual practices of chronically mentally ill persons, including the level of prevalence of HIV infection among them. We do not, unfortunately, have solid data along that line.

COMMISSIONER SerVAAS: My other question was, Doctor Price, Richard Price at Sloane Kettering, I'm sure you know of his work, wrote and told us that 25 percent of his patients present first with dementia, or a neurological problem, or psychiatric, and 9 percent die with no other serious clinical manifestations except AIDS dementia complex.

How do they die? Is that a rare brain tumor, or how do they die?

DOCTOR JUDD: Well, what happens is that makes the brain so dysfunctional that the vital centers that control the autonomic and physiological processes begin to deteriorate, and the patient dies from that.

COMMISSIONER SerVAAS: Doctor Lewin from Hawaii, the State of Hawaii Commissioner, told us of a man -- a physician who told him about a rare brain tumor, and the man had died from it, and Doctor Lewin said immediately, "Well, that was AIDS. Had he had a transfusion," and it turned out that he had, but that he had died and this physician evidently hadn't known that would mean AIDS.

Do you think that our psychiatrists are informed enough about giving attention to the differential diagnosis?

DOCTOR JUDD: I would say that, essentially, the focus on the CNS infection by HIV, and its potential clinical relevance, emerged well into the course of the epidemic. We are in the position, unfortunately, of not having solid data available upon which to base public policy. Do or do not seropositive individual who are asymptomatic genuinely have something that is disordering their thinking sufficiently that it's going to effect their every-day functioning? We just don't have that data right now.

So, I would say there's a lack of understanding, not only among psychiatrists, but among all of the mental health disciplines and, perhaps, even all of health care professionals with regard to a potentially important and rather characteristic phenomenon that occurs, typically late in the AIDS syndrome.

CHAIRMAN CRENSHAW: Thank you very much, Doctor Judd, and I'd like to thank all of the panel members for their enlightening comments. It was a pleasure to hear from you all.

PANEL 5: LABORATORY QUALITY CONTROL AND REGULATION

CHAIRMAN GEBBIE: Our next panel is a one-person panel. It's a real pleasure for me to preside at this, the last panel of our public hearings, and to welcome Congressman Wyden from Oregon to testify on some of the laboratory issues that we've already heard about. Ron?

CONGRESSMAN WYDEN:: Well, thank you very much, Ms. Gebbie, and nothing pleases me more than to see an Oregonian in the Chair. I just want to tell you that I very much appreciate the chance to come and to talk about an issue that I think is one of the most important public health questions in our country today.

Madam Chair, there is just no question about it in my view, that we should not pursue a widespread testing policy for AIDS without assurances that testing will be both accurate and cost effective, and it's my view that today neither of these assurances can be given.

Three frightening factors combine to severely limit the reliability of the HIV test when testing low-risk populations. First, the confirmatory Western Blot test is very subjective. The scientific and medical communities have not determined how to uniformly interpret results that fall between the accepted positive and negative interpretations.

What this means is that what one lab may call a test positive result will be a result that another lab would call a negative result. Patients end up getting unconfirmed results and thousands of tests must be repeated at significant cost to all involved.

Secondly, the accuracy rates for the Western Blot are particularly low in low-risk populations. Recently, my Small Business Subcommittee on Regulation and Business Opportunities worked with the Office of Technology Assessment and found that nine out of ten positive results among low-risk populations was false. In addition, they found, importantly, that one out of ten negative results among high-risk populations were also wrong.

The other thing that we were particularly concerned about that was not a particular emphasis of the hearing, but something that distressed me greatly, is that when the U.S. Army, when the military was about the business of trying to contract to have AIDS tests done, they found that when they sent testing samples to 19 of the nation's largest labs, the premier labs, the biggest ones that do the most tests in our country, 11 of those labs failed. More than half the labs then were not in a position to do adequate testing for the federal government, the Army specifically.

Now, you can only imagine the results that might be obtained by labs that are completely unregulated, when the United States Army finds that more than half of the best, and most large labs in this country can't pass a proficiency test.

We had a specialist from the Army come today, and they said what particularly concerned them is, they didn't even feel their testing standards were very strong. The Army didn't think it was using very stringent standards, and yet more than half of the biggest labs in the country failed what the Army considered an acceptable level of testing quality.

The other point that I wanted to mention, Madam Chairman, is that the vast majority of medical laboratories in this country are unregulated. Earlier this month, the Inspector General, Mr. Kusserow, did a study for my subcommittee, and he determined that there are about 98,000 unregulated physician office labs, and, moreover, there are also a number of labs, like the one that has been featured in the recent American

Medical Association News that we've presented to your subcommittee in the American Medical Association paper, the headline is, "Florida Medic Uses HIV Tests for Outrageous Profit." And, what this kind of testing program involved was testing done from the back of a mobile van, where this mobile van went to massage parlors, and homes, and boats, and just did the testing in the back of the van.

It's an absolute outrage that this goes on, and it's going on because there aren't adequate regulations. I think something ought to be done to stop these kinds of people from taking advantage of those who are frightened in our country and really don't know where to turn.

I think it is also worth reporting, Madam Chair, that with respect to state regulation of medical labs, the General Accounting Office found, in a separate study for our subcommittee, is that 13 states don't regulate independent labs, and 36 of the states, again, a significant majority of the states don't regulate at all the laboratory work that's being done in doctors' offices, and that's where the fastest growth is taking place.

Mr. Kusserow told us that was by far the fastest growing area of medical testing, and it means, literally millions of tests in our country are being done in a wholly unregulated environment.

I think the only other point that I wanted to mention is that there are substantial sums, there are big dollars to be made in HIV testing. It's not just a headline that leaps at you from the American Medical Association newspaper, but we found that despite the fact that the Army does testing for $4.00 a specimen, most of the labs are charging from $40.00 to $200.00 a test. Combine these costs with the high false positive rates inherent in testing low-risk populations, and it's my view that you've really got a formula for trouble.

In the House of Representatives, I've introduced legislation that has been co-sponsored by the leaders of the Health Subcommittee that I serve on, Mr. Dingell, Mr. Waxman on the Democratic side, Mr. Madigan on the Republican side. The leadership of the Health Committee has all sponsored the legislation I have introduced that would require all laboratories doing HIV testing to be regulated and to undergo a regular proficiency testing before we can rely on test results.

And, I would only say in conclusion that I think we're going to need more testing. I think that's an important part of public health policy. So, I want to make it clear that I am not coming out against testing, but it must be testing done in a responsible fashion that addresses the real medical needs of our

citizens that's cost effective, and to just blindly say, as some have in this country, that we should just go with testing policies across the board, and run the risk of the incredible human and social consequences that can come about as a result of those false positive rates, particularly, the rates with the low-risk population. To run those risks, I think is unacceptable.

So, I'm happy to have a chance to be here with all of you. I know that you all have worked very hard to struggle with these issues, and I want to work with you to address these questions.

CHAIRMAN GEBBIE: I appreciate that. I hope you have a few minutes to answer some questions, and I'd like to start with a question about your bill.

As in many other areas with this epidemic, we discover problem areas that are much broader than the HIV epidemic.

CONGRESSMAN WYDEN: That's right.

CHAIRMAN GEBBIE: And, certainly, some of the issues about quality assurance in laboratories and the regulation of laboratories affects a lot of other tests besides HIV.

Can you comment a little bit on why, in your bill that you've submitted, you've limited it to the subject of HIV testing, rather than taking a broader cut across laboratory licensing in general.

CONGRESSMAN WYDEN: This would apply, I appreciate your bringing this up, this would apply to all medical testing. I have talked specifically today about HIV testing, but my legislation would apply across the board to all medical testing being done in independent labs, in doctors' offices, and labs around the country.

One other point that I wanted to mention about why I think this federal role is so important, is that in 1981, the Health Care Financing Administration cut its budget for inspectors by 30 percent. So, I think that because the federal government has cut back on its oversight, particularly, in the budget for inspections in the last six or seven years, that it is really important that we beef up the federal role.

CHAIRMAN GEBBIE: Thank you.

CHAIRMAN GEBBIE: I'll start the questioning on this end with Doctor SerVaas.

COMMISSIONER SerVAAS: Congressman Wyden, I think you do the country a great disservice when you talk about false

positives, because we certainly don't want our patients denying their seropositivity because they hear someone like you say that false positives are a factor.

False positives in the Western Blot, and that's old, old information, it's been debunked in the military and Brooks Jackson has done over 580,000 with not one false positive. That's the University of Minnesota Blood Bank, and the military, Don Burke, one out of 135,000 test, and that was some time back.

The new tests we were shown on the screen, the tests are as good as the lab person not mixing up the tubes.

So that, I couldn't agree more that we need to get the labs certified, and we need to know that any lab doing a test for the confirmatory Western Blot should be certified, and the military handles that with Damon by sending them 40 unknowns every month, knowns, I think they are called, and then they don't even pay them if they are wrong on these tests.

They are able to certify by knowing that they are right, by checking the lab and making sure they are doing accurate work.

So, we can forget about the false positives and needlessly causing patients to feel that they may have been given a wrong diagnosis. They can be given other tests, and look at their T-cells, and a lot of other things to follow up if they have any doubt whatsoever that they aren't truly positive.

So that, when you talk about false positives in the low risk, that's old information.

CONGRESSMAN WYDEN: Well --

COMMISSIONER SerVAAS: It's really been debunk, and I do think you are wrong in stating it in front of this forum.

CONGRESSMAN WYDEN: Well, Doctor SerVaas, I feel that we ought to rely on the experts, and I brought today the Office of Technology Assessment report, and you may wish to put thumbs down on the Office of Technology Assessment, but this report was done for my subcommittee and nothing has been brought out in the last few months since it was done to contradict it.

The bottom line is, with low-risk populations, and I would be happy to give you a copy of the report, I know your Commission has it, that states in the low-risk populations there are nine false positives for every --

COMMISSIONER SerVAAS: Are you talking about Miike's work?

CONGRESSMAN WYDEN: Absolutely.

COMMISSIONER SerVAAS: That's old, and the AMA has had their opinions about it, and a lot of other places have. That's an armchair analysis that isn't the facts. We have the real facts. We have the actual tests, and we don't need to do some extrapolation in Miike's thing. He hasn't done the testing. Don Burke has, and Brooks Jackson, Doctor Jackson in Minnesota has, and I think for us to sit here and conjecture over an armchair analysis --

CHAIRMAN GEBBIE: Doctor SerVaas --

COMMISSIONER SerVAAS: -- is bad forum.

CHAIRMAN GEBBIE: -- I think one of the distinctions is that between the testing done in those few labs, such as the one the Army uses, or the Red Cross one you are using, and the vast majority of laboratories, many of which are totally unlicensed that Congressman Wyden is speaking about, and I think we have to be very precise which we are talking about.

COMMISSIONER SerVAAS: 6 million people tested in the military, 6 million, 568,000 at the Red Cross blood banks, and the Red Cross blood banks have excellent records, and they've checked every single positive that came through and they were all, indeed, positives.

CHAIRMAN GEBBIE: Do you have a question for Congressman Wyden?

COMMISSIONER SerVAAS: I sure do.

CONGRESSMAN WYDEN: Let me, if I might, before we move --

COMMISSIONER SerVAAS: How do you think that we should go about certifying the confirmatory labs in the country? How do you think we should do that, and how fast could it be done, and through what organizations? The FDA isn't really doing that, are they, and CDC. What organization, government organization, how should that be done?

CONGRESSMAN WYDEN: Well, I think we ought to build on all existing programs. Certainly the College of American Pathologists has a program that many labs participate in. That's one of the better programs.

I'd like to see us give the states a significant role in the regulatory process. We're certainly going to need to have a stronger federal oversight process to ensure inspections.

I mean, what we need to dc is build a seamless web so that we use existing programs, state programs, and a federal oversight role, so that everybody is regulated, and I don't think we have to go out and certainly replace things that are working, like the CAP Program.

But, I do think, Doctor, and I want to come back to this point that you mentioned, that we have to look at what the experts are saying. Mr. Burke came to my committee --

COMMISSIONER SerVAAS: Doctor Burke.

CONGRESSMAN WYDEN: Doctor Burke came to our committee, he told us, and this was in late 1987, he tried to work with the private sector. He said, we were interested, be glad to give you his testimony, and you might want to take a look at this, he said, "We tried to work with the private sector. We were interested in contracting out for our AIDS testing. We went to the biggest labs in the United States. 11 out of 19 failed. They didn't even meet the most minimal proficiency standards." He told us, we didn't even think our standards were strong, they failed. He said that, "We decided to do it ourselves," and you might want to read this testimony of Doctor Burke, because what he said about lab regulation is quite a bit stronger than what I've said today. He called for a significant federal regulatory system to do AIDS testing in our country.

COMMISSIONER SerVAAS: Well, Damon Laboratories does 8,000 every night, and they did about 4,000 for Don Burke, Damon Laboratories, for $4.00. That includes confirmatory and everything, and I've researched this because they are willing to do it for other organizations, and not just the military, if we can use that $4.00 across the board. They are the people who told me that for the Red Cross it costs $3.00 to do the AIDS test, all tolled, including the confirmatory following up after two ELISAs.

CHAIRMAN GEBBIE: Do you have a question?

COMMISSIONER SerVAAS: I have a question.

Are you talking about just the ELISA tests, or are you talking about the confirmatory tests, and I certainly would like to know from you, how would you explain that we did -- the military did use the Damon Laboratories, a commercial operation, and that there are others like it, and you are saying that he had to do it himself in-house, in the Army, but yet, to my knowledge right now, they are using Damon also exclusively? How do you explain where you are getting your information?

CONGRESSMAN WYDEN: I have given you an almost verbatim account of what Doctor Burke testified to our committee.

COMMISSIONER SerVAAS: And, how long ago was that?

CONGRESSMAN WYDEN: This was in late 1987, at the hearing where Doctor Miike was, October 19, 1987. He came, he said that we tried initially to use the private sector. That was the heart of his testimony. He said --

COMMISSIONER SerVAAS: But, that's old.

CONGRESSMAN WYDEN: Again, no one has contradicted that, and when you have the Army saying, we didn't feel we could use the private sector, and so we went out and set up our own program, I think that's an important statement.

COMMISSIONER SerVAAS: That's old information. I've been with Doctor Burke as recently as two weeks ago, and they are using the private sector, and they are using Damon Laboratories, and I think that this is not current information you are giving us now.

CONGRESSMAN WYDEN: Well --

CHAIRMAN GEBBIE: Do you have a different question, Doctor?

CONGRESSMAN WYDEN: Let me talk about your point with respect to the ELISA and the Western Blot, because we might be in some agreement there.

There is no question that the ELISA the initial test is largely accurate. The testing, of course, where we have problems is with Western Blot testing. It's a test that's more difficult to do. It's really more important, of course, for the patients, because it's the confirmatory one, and what we learned in our subcommittee is that you really can't separate out the two. The ELISA test is skewed a bit, we were told, to pick up more positives than actually occur. It's a screening test, so maybe that explains that.

But, a good Western Blot is necessary to confirm the positive ELISA results, and we do know that Western Blots can be done well. My sense is, is that because there are so many labs that are unregulated in the United States, that you have a lot of them having problems doing those Western Blots, those confirmatory tests, in an accurate fashion.

COMMISSIONER SerVAAS: Do you feel that there are a lot of poor labs doing the confirmatory tests?

CONGRESSMAN WYDEN: What our subcommittee found, and I will repeat this again, late in 1987, data that has not been contradicted anywhere that we've seen, and we have been looking and will be happy to examine anything that you might have, is that testing, number one, is a significant problem for low-risk populations, that's number one.

COMMISSIONER SerVAAS: That's --

CHAIRMAN GEBBIE: Doctor Primm has a follow-up question on this one when you are finished, Ron. Go ahead.

CONGRESSMAN WYDEN: And, number two, the finding at our most recent hearing of Mr. Kusserow, the Inspector General, that there are 98,000 unregulated labs in the country, I think compounds some of the very serious problems that we do have, particularly on the Western Blot.

COMMISSIONER SerVAAS: I agree that we need to regulate.

CHAIRMAN GEBBIE: Doctor Primm?

COMMISSIONER PRIMM: Congressman Wyden, I think there are a couple of things here that are really important, and the very first thing is that your committee and you should be commended for instituting an expansion of the law that was passed back in, of course, 1967, the Clinical Laboratory Improvement Act law. I mean, that's number one, because we do need some order from up above that goes down to allow states to begin to regulate testing in laboratories and everywhere else. I'll preface what I have to say with that initial remark.

I want to read you something that Helen Singer Kaplan, who is an M.D., Ph.D., who just testified on the panel just before you, and she said in her No. 2 summary of recommendations to the Commission, "Public confidence in human immunodeficiency virus testing has been undermined by the dissemination of misleading information. Actually, the HIV antibody test is among the most accurate diagnostic procedures in medicine."

Now, that's a statement from someone who just left this group. Now, with that in mind, and something else that you had just recently said, you talked about testing being done in ambulatory units, that is, mobile units, and I would like to talk about that just for a moment because that is one way we can actually get out to get those people tested in populations who will not come to testing centers that are designated in many of our cities around the nation.

And, testing from a mobile unit can be just as effective as a test here in the ICC Building. I don't think the edifice or the location of where the test is done has anything to do with it. I think the quality of the test depends upon the person who is conducting the test, and how the sample -- the hematological sample is drawn, what kind of reagents are there, that kind of thing. So, it could just easily be done in a mobile unit as it could be done in an edifice that was an ivy-covered George Washington Hospital, for example.

Now, with that, the point that I would like to try to make here is that, in doing what you are doing, which I think will be helpful to the profession, also is to each time you maybe would attack one of these things and say it's bad, that you would also say it's bad because of whatever the reason is, and that it could be good if X was done. So that, we would enhance the credibility of the test itself, rather than to destroy the credibility.

And, I think then we would be in concert with one another.

There is another confirmatory test that is almost 99.9 percent like Ivory Soap, pure, and that is the immunofluorescent assay confirmatory test that is done after two Western Blots, that unquestionably, if that's positive, that it's not a false positive, it's a real positive.

So, I wanted to pass that information on to you, so that you would understand some of the feelings that some of my colleagues, indeed, do have.

CONGRESSMAN WYDEN: Well, let me, if I might, try to respond, and, again, Doctor, I have always felt, as a member of the Health Committee, that I should be looking to the experts. And, Doctor Miike and Doctor Burke were the two that I cited as a result of my initial hearing.

With respect to the home test kits, and the vans or things of this --

COMMISSIONER PRIMM: Not the home test kits. I didn't refer to those.

CONGRESSMAN WYDEN: Vans and --

COMMISSIONER PRIMM: I referred to a van that has a setup of just like you would have it set up right here, that could happen. I've seen many testing units like that for tuberculosis, for x-rays, for other kinds of problems, syphilis, for example. They don't do the test in the actual van, but they could draw the blood, and in some instances you could do actual

hematological testing in a mobile unit. We do it, you know, in the Army, field hospitals. I don't know whether it's perfect to do it.

CONGRESSMAN WYDEN: I would say two things. First, I think my concern has always been whether there is some regulation, whether there is some scrutiny, whether there is some professional oversight, and what we have been told most recently, again, by another independent expert, Mr. Kusserow, the Inspector General for the Department of Health and Human Services, is that there are almost 100,000, he said 98,000 unregulated labs.

Now, the context that you have given, if there was some degree of regulation, and scrutiny, and inspection, I've come here to say that I favor more testing. I think we are going to need more testing.

COMMISSIONER PRIMM: Sure.

CONGRESSMAN WYDEN: But, I think we do a disservice with these proposals to just go out and indiscriminately test when there is such an unregulated environment, and I will continue to make my policy judgments on the basis of the experts.

Now, I think you are also aware that the Food and Drug Administration, and Doctor Young in particular, have expressed great reservations about these home test kits. I feel that they are on the right track. I think that they've looked at it, they've assessed it in a responsible way. We know what their principal concern is, which is that they don't feel that it provides a forum for counseling, and dissemination of responsible information in terms of accurately getting these results.

So, I think that as long as we make our judgments in this field on the basis of what the public health authorities and experts like Mr. Kusserow are telling us, we're on sound ground, and as a member of the Health Committee that's the way I conduct our affairs.

COMMISSIONER PRIMM: Well, I want to commend you, Congressman, and, unquestionably, I'm in symphony with you, not in cacophony. I am perfectly in accord with regulating and having people meet certain standards, and I can recall very vividly when former Mayor Diane Feinstein brought before us a testing kit in California that was a home testing kit. I was not at all in favor of such a thing, because it had not been regulated, looked at very carefully, and certainly counseling did not accompany that. So, thank you very much.

CONGRESSMAN WYDEN:: Well, and I think that you have hit on one of the key kinds of questions, and, that is, how do we

get up testing quality, and I think one of the keys to getting it up is to have the kind of regulatory system, licensing, inspection, some concern for meeting a proficiency standard that we're discussing.

CHAIRMAN GEBBIE: Doctor Crenshaw?

COMMISSIONER CRENSHAW Yes.

I don't think you'd get argument from any member of this Commission that there needed to be regulation of private laboratories, and anything we can do to improve that would be all to the good.

I think there are several issues that get mixed up, and separating them has significant advantages.

I would encourage you, as a matter of fact, to extend this overview beyond AIDS, because this --

CONGRESSMAN WYDEN: I'm sorry?

COMMISSIONER CRENSHAW -- to extend this overview of laboratories beyond AIDS, because laboratory error in terms of malignancy, and hepatitis, and a variety of other things is of the same order and terribly important.

However, I do want to underscore what Doctor Beny Primm said and what Doctor SerVaas said, and, that is, any time this issue is raised, because the public is so confused, we must underscore the value, the specificity, the accuracy of the tests, in combination, rather than talking about the drawbacks of one test as though that's all that the medical community does.

I also think it is very important to take a proactive and a positive "can do" attitude, which is, we can improve the quality of the test, and it's good to get it done, because often the opposite message comes along. It's sort of like a "can't do" philosophy, and, obviously, you are trying to work to get this accomplished.

I think we also have, as a Commission, heard from over 500 witnesses, is that not correct?

CHAIRMAN GEBBIE: 600.

COMMISSIONER CRENSHAW 600 after today, and many, many of them have dealt with the testing issue and you'd just be amazed in our brief nine months, actually, in operation how rapidly information has changed, and how much we've learned on a daily basis.

But, it worries me that we are treating the HIV test, which is the best test of its kind, with a kind of double standard, because other tests, like the tuberculin skin test that we use for screening, and hepatitis B, which we use for the blood, are remarkably faulty, but we still find them of value in spite of the fact that they don't catch all cases.

COMMISSIONER PRIMM: "VDRL"?

COMMISSIONER CRENSHAW: Pardon?

COMMISSIONER PRIMM: "VDRL"?

COMMISSIONER CRENSHAW: The VDRL, I mean, we find them of value, we apply them in perspective. We don't throw them out because there is an inaccuracy rate, and compared to them this test is a shining jewel.

So, I really would emphasize that if we want to inspire voluntary testing throughout our nation, we have to inspire confidence in the test. And, what you are doing can be turned tremendously to the good by supervising these laboratories, as long as it doesn't get mixed in with the message, the confusing message that the test itself is not dependable.

CONGRESSMAN WYDEN: Well --

CHAIRMAN GEBBIE: Did you have any other questions?

CONGRESSMAN WYDEN: -- let me see if I can respond beyond what we've already talked about today.

My committee, as a result of the HIV test, went back to the College of American Pathologists and asked them to do another analysis of more than 20 different tests, so we have been looking --

COMMISSIONER CRENSHAW: Great.

CONGRESSMAN WYDEN: -- in a comprehensive way at everything from cholesterol tests, you name it, and again, what the data showed, and remember, this is the best outfit, I mean if everybody was like the College of American Pathologists we'd have a relatively small percentage of problems, but the best laboratory organization that people participate in voluntarily was reporting significant errors from major sorts of things, platelet counts, and things that were serious sorts of business.

So, I don't disagree with the idea that we have some real problems with respect to beefing up lab quality all across the board. So, I think we are all in agreement on it.

Where I think, perhaps, we disagree, though, is that in this area where we are now, because of your good work, and others, about to make major policy judgments on AIDS, I think we ought to focus on specific questions also with respect to the quality of AIDS testing. And, I must tell you that I am not at all convinced, as somebody would like to see more testing generally, that testing of low-risk populations is cost effective at this time. And, I think we know that the Western Blot is still used in many, many instances around this country, and I am not convinced yet that we have gotten that accuracy level up to the point where there should be just massive testing of low-risk populations.

And, I agree with you, we want to beef up every possible way to encourage people to test voluntarily. We want people to come forward and test voluntarily, but I think they deserve the facts, and, again, what I have gotten from my subcommittee was data that was presented after an analysis of many, many labs, by Doctor Miike, after it came out there was this great uproar, but no one has criticized or contradicted his data. It has not been contradicted.

COMMISSIONER SerVAAS: It has been contradicted. Don Burke has contradicted it, and if you talk to Don Burke now --

CHAIRMAN GEBBIE: Doctor SerVaas --

COMMISSIONER SerVAAS: -- you can find out it is cost effective to test the low-risk populations. We know that.

CHAIRMAN GEBBIE: One thing I think we've learned continuously in these issues is to watch our vocabulary, and one of the distinctions that might be important to make is the difference between the quality of a test in its abstract or perfect sense, from the performance of any laboratory, meaning how well do you do something, because the lousiest lab can take a perfect test and mess it up, and that's more what you are talking about --

CONGRESSMAN WYDEN: Exactly.

CHAIRMAN GEBBIE: -- than the abstract quality of any of these tests, and I think that's helpful.

You said you had -- I don't want to keep you too long, because I know we committed to being done at 4:00, and I've got a couple of quick questions.

COMMISSIONER CRENSHAW You brought in another issue that I think is important, but also, completely separate.

Assuming the test is reliable, and that the quality of the labs are brought up to speed, and that until that time it is only one in quality labs that are already up to speed, there is the question of cost effectiveness, and this is a dilemma that we really deal with.

One of our witnesses this morning, Doctor Masters, raised the issue that by the time it's considered cost effective by the economists, there's a lot of infection out there. And, to me, that's not cost effective at all in the cost of human lives.

Also, factored into the cost effectiveness in the calculations that I have seen has not been the cost savings of the prevention that can be accomplished with test-linked counseling, particularly with the panel we just had on how to keep low-risk groups low, making use of a negative test, not considering that irrelevant, but linking that with some guidance and advice on how to maintain an uninfected status.

And, I just wish that somehow there were a way to quantify human life and factor that into these mathematical cost effectiveness questions, but there doesn't seem to be a way, and we have to deal with this in a softer zone. So, I would just propose that as food for thought.

CONGRESSMAN WYDEN: Well, I think those are, of course, important issues. I have Doctor Miike's analysis he did for us, again, and what he found with the low-risk populations, which were his Peoria, Illinois blood donors, that it cost $49,000.00 to $76,000.00, more than $76,000.00 to identify -- the table is entitled, "Costs Incurred to Identify One Truly Positive HIV Antibody Positive Specimen for Low-Risk Populations."

So, again, I think these are important figures for us to consider, and -- we wish to work with you.

COMMISSIONER SerVAAS: We've actually --

CHAIRMAN GEBBIE: Excuse me, Doctor SerVaas. I'm moving on to the last question at this point, because we've gone overtime, and my last questions are very practical ones relating to your bill, specifically.

I think for our record, it would be important to know whether you have actions scheduled to follow up on the bill, and what is your sense of its likelihood of passage at this point?

CONGRESSMAN WYDEN: Madam Chair, the bill does three straightforward things to try to shore up laboratory testing. There would be annual inspections, mandatory licensing and proficiency testing for all labs, including those in doctors' offices.

The legislation requires that proficiency testing use state of the art targets to assess labs' performances, and then it requires the Department of Health and Human Services make available training and technical assistance to labs, so that if there are things they need to do to perform adequately, they would be assisted in that way.

Also, as you and I have talked about, Madam Chair, we hope to be able to provide some funds to the states to help get this off the ground. There is no question that there will have to be some phase-in sort of period, particularly for physician office labs, because this would be a major change on health policy. But, my sense is, is that we can get this legislation passed, we are going to try and move it in this session of Congress. It has the bipartisan support of the leadership on the Health Committee, Mr. Madigan, the Ranking Republican on the Health Committee, is a co-sponsor of the legislation, and I'm very hopeful that we'll be able to get it passed in this session.

And then set about the difficult task, and, particularly, to regulate close to 100,000 physician labs means we are going to have some phase-in period to get all of those into some sort of system.

CHAIRMAN GEBBIE: Does this bill have a companion bill in the Senate?

CONGRESSMAN WYDEN: It doesn't right now. A number of offices in the Senate have talked to us. Since we did the primary inquiry in the House, I felt we ought to make sure we had a bipartisan bill moving in the House, and we do now, and I think that there will be action, and a number of my colleagues in the Senate have already begun, as you know, to look at the lab issue.

CHAIRMAN GEBBIE: But, you are completely through the hearing stage in the House, or not?

CONGRESSMAN WYDEN: No. We have not had a hearing in the Legislative Committee on it, but because Mr. Madigan, the Ranking Republican, and Mr. Waxman, the leadership of the Health Committee, are co-sponsors of the bill, I think we will be able to move this legislation in this session, and get it all the way through the legislative labyrinth.

CHAIRMAN GEBBIE: Good. I think members of this panel, as individuals, as I am, will remain very interested in the bill, and, certainly, as we work on our report we'll want to stay in touch with you and your staff.