TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

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Denver Colorado
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NATIONAL COMMISSION
ON
ACQUIRED IMMUNE DEFICIENCY SYNDROME

HEARING

Friday, June 7, 1991

8:42 a.m.

Stapleton Plaza Hotel

Denver, Colorado

COMMISSION MEMBERS PRESENT:

- June E. Osborn, M.D.
- David E. Rogers, M.D.
- Scott Allen
- Harlon Dalton
- Eunice Diaz
- Donald S. Goldman
- Larry Kessler
- Irwin Pernick
- Michael Peterson
- Valerie Setlow

STAFF PRESENT:

- Frank Arcari
- Tom Brandt
- Maureen Byrnes
- Stacey Bush
- Fran Page
- Joan Piemme
- Karen Porter
- Nicole Ryan
- Jane Silver
- Ellen Tynan

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PROCEEDINGS

DR. OSBORN: Good morning. We're actually not as late as it looks because I am not going to spend much time saying anything more than good morning and welcome to our witnesses and the people who are joining us.

We're looking today, as we commonly do, we spend bits of time all the time hearing about issues and so forth, and then every once in a while it helps a great to focus on them. So this morning's set of witnesses will help us to focus directly on issues of civil rights and discrimination.

We are exceptionally pleased to have Nan Hunter to start us off, and I am exceptionally pleased that Harlon Dalton has agreed to coordinate things and keep the flow going.

So Harlon, let me turn it over to you.

MR. DALTON: Okay. You all may think I had something to do with this hearing, but it is not true. The commissioners who most, I think, pushed for us to focus specifically on civil rights--even though as June just said, we hear about it in virtually every hearing--the folks who pushed specifically were people like Charles Konigsberg, who is health commissioner for the State of Kansas, and Scott

Allen, who acts as a "wannabee" lawyer, but in fact is a Baptist minister from Texas.

[Laughter.]

MR. DALTON: Indeed I wasn't even involved in the invitation to the panelists. I say that because a number of them are friends of mine. I'd like to get the credit, but I have been too busy trying to get you all a free flight to Denver.

I am in fact not going to introduce the panelists in part because I do know a number of them personally and probably couldn't resist telling you things about them they don't want you to know, so I will just simply ask them to say a word or two about themselves and then carry on.

The overview will be from Nan Hunter, and Nan, you have about 20 minutes, and knowing you, I know you'll stay within your time limit and enlighten us all.

STATEMENT OF MS. NAN D. HUNTER

MS. HUNTER: Thank you very much.

My name is Nan Hunter. I am a former director of the ACLU AIDS Project and now a professor at Brooklyn Law School.

I'd like to start by thanking the Commission for the opportunity to testify and for having this hearing and indeed for all the work the Commission has done so far on the issue of civil rights for people with AIDS and people with HIV disease.

I would like to divide my remarks this morning into two parts--first, a discussion of what I believe amounts to an immediate crisis or series of crises in the area of civil rights and AIDS, and secondly a discussion of some of what I would suggest to the Commission are long-term civil rights issues as we begin the second decade of this epidemic.

First, as to the short-term. In some ways, I wish this hearing had been held perhaps six months ago because I think that six months ago I would have been at least a bit more sanguine and optimistic about the questions involving civil rights of people with HIV disease in terms of what the law has achieved for people in the last five years.

I certainly would have pointed to the enactment of the Americans with Disabilities Act, which I think stands and certainly still stands as probably the single most significant breakthrough in this area.

I also would have pointed to what I think is an impressive network of State laws protecting and guaranteeing very stringently informed consent for people who are approaching or seeking HIV testing, the pretty much universal rejection of calls for quarantines, which were typically under active consideration five years ago, and what I then probably would have characterized as the abandonment of at least many of the early proposals for mandatory HIV testing, two of which I have thought about pointing out, being the calls for premarital testing and what seemed to be the imminent abandonment of forced HIV testing for immigrants entering the United States.

Obviously, some of those achievements--the ADA, the rejection of quarantine, the abandonment of premarital testing--still stand, but I think others are today under renewed and in some ways enhanced attack. In recent days and months, obviously we have seen what is perhaps at best a serious setback and perhaps a rejection of what we had thought was the recognition by the government that forced testing in the immigration field did not make public health sense. We have seen new calls and additional calls for mandatory HIV testing, and I think we are about to enter a renewed debate over what I had considered to be a really very basic and fundamental principle of informed consent and specifically written informed consent.

But by far I think the level of public hysteria that is most significant right now and is most serious right now involves the issue of testing of health care workers and to some extent hospital patients. This is an issue which is literally in the news almost all the time. It has come in the last six months, I would say, to really dominate the discussion of civil rights for people with HIV.

I read in this morning's newspaper once again that new guidelines from the Centers for Disease Control are imminent. I think it is important to note that those guidelines will be proposals, that is, those guidelines will be published as proposed recommendations which will then themselves be subject to public comment and review. That will trigger yet another, even greater, sort of massive degree of attention to this particular issue.

I'd like to try to frame this issue for the Commission as an immediate crisis, but also one where I hope the Commission will think about it and I would encourage people to think about it on the level not just of what it means for infected health care workers or infected patients, but also what it means for really the central principle and one of the underlying principles that we've had to deal with in the course of this epidemic, and that is the question of risk and what it means to assess risk.

In many ways I think the issue reprises for us some of the early issues of the epidemic, some of the issues that we now take for granted as being easy issues. The school children issues, for example, were not such easy issues five or six or ten years ago. They were issued which involved debates in which physicians, for example, were called upon to discuss whether it could conceivably be possible that a school child could transmit HIV. What about HIV in saliva? What about the school child who bit another school child? What about the incontinent school child?

And gradually, over a period of years, we had those cases and we litigated those cases. Quite specifically, for example, the ACLU of Southern California litigated a case in the early to mid-Eighties involving a school child with AIDS who actually bit another school child in some school altercation, the Thomas case.

The Martinez case in Florida was popularly portrayed in the press, and I'm sure many of you remember it, as the "girl in the glass box" case. This involved a school child who had multiple disabilities and who for that reason was incontinent and as to whom the lower court judge ruled that there was some risk of transmission, that it could not be said that there was zero risk of transmission, so the lower court authorized and implemented the rather infamous "glass box" in which that child initially went to school. That case was ultimately reversed, and it was reversed on the basis of a standard adopted in the Supreme Court in a tuberculosis case, the Arline case, which really set the standards in many respects for HIV cases because it involved a disability discrimination law issue, and it involved a condition that was communicable. Indeed, tuberculosis in some of its phases is much, much, much more communicable than HIV ever is.

In that case, one of the things which the court held was that the standard had to be the standard of significant risk as measured by objective medical evidence. Based on that standard, the 11th Circuit Court of Appeals in the Martinez case, for example, ruled that that decision, that "glass box" decision if you will, had to be overruled; it had to be set aside because although the risk could not be said to be absolutely zero, it was so remote and so theoretical that when placed in perspective, it simply could not justify what was being done to that child.

I think the health care worker debate forces us to reconfront that fundamental issue of how we measure risk. What does "significant risk" mean? It must mean that the risk, although not necessarily zero, must be measurable; it must be appreciable; it must be the kind of risk that is not in the category, basically, of being struck by lightning.

And I think it is important to note also that the significant risk standard did not originate even in the tuberculosis case much less in an AIDS case, but it originated in a series of other disability cases involving questions of safety. One of the primary cases which was the origin of the standard in fact involved a hearing-impaired school bus driver as to whom the argument was made that there was a risk that even with a hearing aid, there was still a risk to the safety of the children in the school bus, that the hearing aid could suddenly go dead, the hearing aid could fall out, that this person was not capable of performing in that situation where safety was at issue. And the 3rd Circuit Court of Appeals very wisely said that we must have a risk standard which is realistic, and they adopted the significant risk standard.

In the health care worker setting, I think it is extremely important that both as a matter of law and as a matter of response to the CDC guidelines--which certainly involve questions of law--and equally important as a matter of public debate, that all of us take the opportunity, and I would especially urge the Commission to take the opportunity, to enter into that debate with I would say one major goal being the affirmation of this significant risk standard.

In my mind, it has two parts--one, what the measure of risk is, that it must be a significant risk; and secondly, the other part, the objective medical evidence portion of that.

To my mind, the phrase "objective medical evidence" doesn't connote just impartiality, but also connotes a sense of perspective, a sense of comparison, a sense that you put the risk here from whatever the particular procedure is or whatever the particular situation is, in some kind of framework that compares it to other risk in the health care setting, in other settings, and frames it in a way that does not permit policymakers to single out HIV or to single out AIDS for some exceptional--in my mind, this is the true HIV exceptionalism--for some kind of exceptional standard of absolute safety that is never met and never adhered to in any other situation, and that we recognize, of course, that there is an enormous amount and a continuing enormous amount of hysteria that attaches to this disease and stigma that attaches to the people who are affected by this disease, and this wildly distorts our assessment of risk and of what real risk is.

But I urge the Commission to take on this task because not only is it a crisis now, but I believe that it is likely to reach even more critical levels in the weeks and months to come, and to try to frame that debate or reframe that debate and shape the public attention to that debate in ways that look to what the fundamental principle is of risk and risk assessment.

The other issue that I want to point out in terms of where I think the immediate questions lie today is the issue of written informed consent prior to HIV testing. There is a proposal which I'm sure many of you are aware of that will go before the American Medical Association House of Delegates later this month which recommends amending State informed consent laws, which I now think are in really quite good shape, to remove the mandate for written informed consent when diagnostic testing at a clinic or a physician's office is initiated at the physician's discretion.

The proposal does not call for an end to informed consent or for an end to the use of written informed consent in the hospital setting, but it does represent, by allowing an end to written informed consent in clinics, in what I would imagine to be a lot of public health settings and physicians' offices, from principles of guaranteeing individual autonomy which underlies the law of informed consent.

Informed consent law accords the patient the right to make the decision about balancing risk and to make the final decision about which risk that patient will undertake. The extension of informed consent principles to a medical test such as the HIV test which medically carries no special risk--it is a blood test, so I think the tendency often on behalf of medical professionals is to think of it as not a big deal because it is not like surgery in terms of what the medical consequences are--but it represents a very important recognition of the social consequences and the social risk. That decision and the kind of individual dignity principles which are represented by that decision in terms of who makes the call on which risks are going to be undertaken, I think it is extremely important that that principle of specific informed consent to this test and not just being able to do the test on the basis of a general informed consent, and written informed consent, be adhered to.

There are other examples, and again I think it is important to think of HIV as not being the only situation in which this occurs; there are other examples of requiring specific and written informed consent to procedures which are not extraordinarily dangerous in terms of morbidity or mortality. One of the examples that certainly exists in the Medicaid field quite specifically is that of consent to sterilization procedures for Medicaid patients. That special consent procedure arose out of something in some ways very comparable to the stigma that attaches to people with HIV; it arose out of a pattern and history of the abuse of patient consent. There have been multiple studies done documenting indeed the degree of surreptitious HIV testing that goes on in hospitals and in other settings. So the tendency here to move toward a disrespect for patient autonomy in this area I think is extremely disturbing.

I also think it is extremely disturbing in the context of the shifting or the broadening, I would say, population base of the epidemic. Why now is this the moment, as the population of HIV patients shifts especially into low-income and minority communities? Why now are we moving toward abandonment of the guarantees of informed consent?

To me, this resonates--and I don't mean to suggest any specific motive--but I think it is one that this Commission could quite appropriately bring to the fore of public discussion as a question that needs to be very, very seriously considered and monitored, that we do not want to look back ten years from now and observe that just as population shifts occurred and just as more disempowered people are affected by this epidemic that, lo and behold, isn't it interesting that at that moment we shifted away from a stronger protection of the rights of patients.

This point actually leads me directly into what I wanted to talk about briefly in the context of sort of long-term issues, and that is that I want to suggest for the Commission a few specific, very general areas that I would suggest may shape or should be considered as we look not at what I perceive to be really an immediate crisis that is going on now, but civil rights issues into the next ten years of the epidemic.

One of the sources for this actually is a study that the Ford Foundation funded together with the ACLU funding of the ACLU Aids Project that began in late 1989. The focus and purpose of that study was to identify issues that would form the basis, new issues that would form the basis for some of the most perplexing legal questions and civil rights questions in the future of the AIDS epidemic. So partly I would like to share with you what some of the results of that are.

One theme of that I think certainly is that as the population broadens to include not only the populations affected by AIDS to date, but to some extent the epidemiology shifts, that there is a need to think about how the focus on civil rights issues, or what some of the civil rights issues will be in the second stage. The civil rights issues from the first stage no doubt will continue, but I think there will be new civil rights issues in a sense if you will, issues concerning the debate, for example, as to mandatory testing of pregnant women, or issues concerning whether adolescents with AIDS have adequate access to testing with confidentiality and consent protocols in place, that is, adolescents being persons who are legally usually not considered competent to agree to a test because they are minors. As the law now stands--in part because these issues are only beginning to arise--they have not been the subject of as much attention, naturally, as some of the issues that lawmakers have addressed in the first ten years, issues of confidentiality and so forth.

But I would urge you to think prospectively about what some of the issues that legislatures and other lawmakers are going to have to address as the epidemic continues.

A second point, which I single out as a point of its own to highlight it, is the issue of access to health care as a civil rights issue. Together with the growing consensus that I think we see all around us about the need to reform American health care and the American health insurance system, we certainly see in AIDS a particularly brutal version of that in which access to care makes this incredibly stark contrast between what can be sudden death or years of potential life.

So I urge you as the Commission to identify access to health care and that kind of reform as a civil rights issue and as an issue that is of extraordinary importance to people with this disease.

Lastly, the issue that I would urge the Commission to think about and to look at, that I think has become an issue and will continue to be an issue, is the interplay between public health systems and criminal justice systems.

We have seen in recent years a number of instances in which prosecutors have charged people with crimes, sometimes for acts such as spitting or biting, acts which have no realistic possibility of transmitting the virus but which, because of the elements of the crime involved, whether it is attempted murder or assault or whatever, one can make an argument that these particular acts fall within those elements of crime. In a number of instances we have seen such prosecutions upheld.

These are situations which I think if you put them in the public health system context, indeed, perhaps, in exactly the same jurisdictions, the public health authorities would not have prosecuted people, for example, by automatically locking them up or seeking to lock them up pursuant to a quarantine situation.

So you have an enormous divergence here of result and of process, and I think this is driven by a number of things in terms of the structure of the law and in terms of the sort of institutional imperatives of people in prosecutors' offices, who typically have an institutional imperative to sort of charge crimes that are possible to be charged.

But I think that it has a great cost in public health terms; it sends the wrong message about what spitting or biting can do to people; it sends the wrong message about what happens to you if you are identified as being HIV-infected, which of course sends exactly the wrong message that everyone has been trying to send for the last ten years, about what the consequences are essentially of coming forward to be tested.

So I would urge the Commission also to look at this issue and to think about it in terms of recommending that these prosecutions, although they may be technically possible, are unwise and to urge public health authorities and public health principles to govern in these situations, because it seems to me that the public health concerns are truly the most important in these situations.

Those are what I would offer as some beginning remarks. I know that many of these issues are going to be elaborated on by other people in the course of the day, and again, I thank you for the opportunity to testify, and if there are any questions at this point, I'd be happy to respond.

MR. DALTON: Thank you, Nan. That was really quite wonderful, and as a lawyer and professor both, I am impressed.

The process--and around the table are a number of sharp legal minds, anxious to become part of the discussion--so the process from this point forward is that Nan I hope will stay right where she is; the other three people flanking her will be the first panel, and we'll introduce yet another topic, which is the Americans with Disabilities Act. When they are finished, then all of the participants around the table will have an opportunity to speak to that issue, although I suspect it may be hard to restrain them from addressing some of the other issues that Nan put on the table.

We will then take a break, and then the folks sitting at the front of the room will be replaced by the people sitting on the side, who will each have a chance to also speak to the question of civil rights issues in the Nineties. So it will be a bit of a roundtable or free-for-all, and of course, the commissioners will mix in as well.

That's sort of a complicated explanation of the process, but the bottom line is that, Nan, you have opened up some wonderful issues, and you are quite right, others will speak to them, including members of the Commission.

But for the moment, we're going to have about 35 minutes on the subject of the Americans with Disabilities Act and the three panelists who will at least open up that issue are, from the Commission's left, Bill Rubenstein, who is the Director of the ACLU's National AIDS Project; Curt Decker, who is the Executive Director of the National Association of Protection and Advocacy Systems and Co-Chair of National Organizations Responding to AIDS, or NORA, Civil Rights Task Force; and Katie O'Neill or Kate O'Neill--I never know which one is going to show up; it depends how sophisticated she is feeling--who is head of the HIV/AIDS Project at the Legal Action Center in New York.

They tell me, Bill, that you're going to start, and with 35 minutes altogether, that means about 7-1/2 apiece.

STATEMENT OF MR. WILLIAM B. RUBENSTEIN

MR. RUBENSTEIN: Thank you very much, and I thank all the members of the Commission for having me. It is a great opportunity to testify, and I appreciate being here.

I had some written comments which I submitted which spoke to some of the limitations of the Americans with

Disabilities Act, to give you an idea of what is left open, what needs to be done, recommendations the Commission can continue to make.

As the first speaker on this panel, though, I also feel some obligation to give you some sense of what the Americans with Disabilities Act does and what the importance of it is, before I speak briefly to the limitations of it, which are outlined in my testimony.

So let me just give you a few minutes of background about the Americans with Disabilities Act, where it comes from and what the importance of it is for people with HIV disease.

The law was passed last summer, on July 13th, and signed into law by President Bush on July 26th, 1990. What you should know for these purposes, though, is that the law is actually not in effect yet; it goes into effect in a staggering form over the next four years, actually, or the next three years.

For people with HIV disease, of main importance, the first provisions will go into effect in January of 1992. The importance of the act to people with HIV disease is that it plugs several holes with regard to antidiscrimination laws that were in existence. Prior to passage of the act, what was in existence was the Rehabilitation Act of 1973, a Federal law which we refer to as Section 504, which protected people with disabilities, including people with HIV disease, in Federal agency employment and places that got Federal funds. And since 1988, the Fair Housing Act has protected people with disabilities in all housing, private housing accommodations, from discrimination as well, including people with HIV disease.

Outside of that, and of main importance here, is with regard to private employment in places of public accommodation, where people with disabilities were left to State antidiscrimination laws and local antidiscrimination laws.

What the ADA does is it extends Federal protection into the private workplace for people with disabilities, and Federal protection in places of public accommodation for people with disabilities. That kind of general Federal protection all across the United States is of terrible importance. In places like New York City, where we have an antidiscrimination law that works fairly well for people with disabilities, it may be less important, but in places like

Tennessee and Alabama and all kinds of other States in the United States where they don't have such good laws, or in many places, don't have laws at all, the existence of the ADA is really the first protection people with disabilities and people with HIV disease have in the private workplace and in places of public accommodation.

The law itself has four different titles to it. Title I deals with employment; Title II deals with public services and transportation; Title III deals with public accommodations, and Title IV deals with communications.

Although it is a new law, the principles of the ADA draw on two older laws. The substantive provisions of the ADA come out of the Rehabilitation Act, Section 504, and the regulations that were enacted by the Department of Health, Education and Welfare in 1977 to enact the ADA. Those substantive notions from Section 504 are imported into the substantive sections of the ADA, which I'll touch on in a minute.

The procedural process of how you get remedies if you are discriminated against under the ADA are taken from the Civil Rights Act of 1964, from Title VII, which protects people against discrimination on the basis of race, sex, religion and national origin. So those are the two laws that are already in existence, and their contents are picked up in the ADA and taken from there.

With regard to the substantive provisions of the ADA and how it protects people with disabilities, particularly people with HIV disease, there are really four main concepts that float around in antidiscrimination law. The first concept has to do with the definition of disability itself, and disability is defined with a three-part definition, the first part being that you have a physical or mental impairment which substantially limits you in one or more major life activities; and the second part being that people are protected if they have a record of such disability, and the third part being that they are protected if they are regarded as having such a disability. In addition in the ADA, people are protected if they associate with people who have such disabilities as well.

It is clear from the ADA that people with HIV disease, the whole spectrum of HIV disease, including fullblown AIDS and including asymptomatic HIV disease, will be protected by the ADA; that this concept of the definition of disability covers them.

The limit on that--this is the second concept, which Nan touched on--is the idea of direct threat. An employer, for instance, has a defense in the ADA if the employee poses a direct threat to the health and safety of others. "Direct threat" is defined in the ADA as the substantial risk standard that we've been talking about.

The third substantive concept that is imported into the ADA from existing law is one of reasonable accommodation. This means that employers have to make reasonable accommodation, they have an obligation to reasonably accommodate people with disabilities. So if you are thinking of hiring someone with a wheelchair, if the wheelchair doesn't fit under a desk, for instance, the employer has the obligation of raising the level of the desk to the person with the wheelchair can work.

For people with HIV disease, the concept of reasonable accommodation may be most important in terms of setting up flexible schedules. If someone needs to go to a doctor once a week or once every other week and needs an hour off of work in the middle of the day, the employer will have the obligation of making that reasonable accommodation for someone with HIV disease.

The fourth and final concept is one of undue hardship, which is simply that the idea of reasonable accommodation doesn't extend forever; it has a limit on it, and the employer doesn't have to go over that limit, doesn't have to do something that would cause undue hardship for the employer in providing the reasonable accommodation. Undue hardship is defined as "significant difficulty or expense", and how that will actually work out is something that we'll wait to see.

As I said with regard to the procedural remedies for people who are discriminated against under the ADA, it picks up from Title VII. With regard to the employment section, the Equal Employment Opportunity Commission is the agency that oversees it. If you file a complaint with the agency, typically they give you a "right to sue" letter, and you can then go into court. Your relief is similar to that under Title VII, which at the current time is one of injunctive relief, including back pay and attorneys' fees. People cannot get money damages other than back pay for discrimination under Title VII nor under Title I of the ADA at the current time. If the Civil Rights Act of 1991 is enacted as it currently is, you will be able to get money damages for this kind of discrimination.

With regard to the public accommodation section of the law, it is enforced by the Department of Justice. It is unclear whether they will set up an administrative apparatus for taking complaints, but people who are discriminated against under that can go into court, again get injunction relief. Additionally, the Department of Justice can enforce that section of the law and can seek civil fines and money damages for people who have been discriminated against.

That's a little bit of an overview, and let me touch on what is in my written testimony, which are some of the limitations. I really made three points there about what this Commission can think about with regard to the ADA and what needs to continue to be done even though this wonderful law has been past.

The first point I wanted to make was that it needs to be implemented; the existence of the law in and of itself is not enough. There, I said that there are three different components. One is educating people about the law, particularly educating people with HIV disease about how the law affects them and what it means for them.

Second is making the administrative agencies that are going to be the primary enforcement mechanisms here work, in a sense, making them have sufficient funding and sufficient staffing to make them be able to enforce the law; and also I think from the point of view of people with HIV disease, making the agencies that are going to be enforcing these laws for all people with disabilities understand the specific problems of people with HIV disease as well.

A third point with regard to that is making legal services available. The existence of a law like this, which is a very complicated law, in and of itself won't help people with HIV disease if they don't have the legal services available that can get them access to the courts or to the administrative agencies that can solve the kinds of discrimination they are facing.

The second point that I made in my testimony is that there are some issues in the ADA, which you have already heard some discussion of, that we are going to have to wait and see how they play out with regard to experience. I touch on three of the issues there. One has to do with the availability of employment benefits, particularly health insurance benefits, for people in the workplace. A second has to do with how the testing provisions and HIV testing provisions of the law will play out. A third has to do with how the significant risk standard will be interpreted, which is something Nan has already talked about to some extent.

And finally, the last point I wanted to make is that there are a number of civil rights issues that simply are not covered by the ADA at all, and it is important for the Commission to recognize that these issues exist and that there are still major areas of civil rights law which are not covered and which we need to continue to be vigilant on and seek remedies for in other ways.

One major limitation of the ADA is that it does not apply to employers with fewer than 15 employees, which is quite a lot of people in the United States. Second is that it probably won't apply, basically won't apply, to the sale of individual health insurance. The fact that people can be HIV tested and not gain access to individual health insurance will not be remedied by the ADA.

A lot of issues about the funding of the public health care system, the problems with definition of women, for instance, in AIDS and how that works out for getting benefits, the basic underfunding, the Medicare waiting period--all the problems of access to health care are not necessarily going to be hit head-on by the ADA.

There are a number of gaps in the area of family law; some of the criminal law issues, Nan touched on at the end of her testimony. A lot of these issues will not be solved by the ADA. And while the passage of the law was terribly important for people with disabilities, it is really not a panacea, and there are many recommendations that a commission can make and much kind of vigilant activity that we have to engage in.

Thank you very much.

MR. DALTON: Thank you, Bill.

While you were talking, I glanced through your testimony, although frankly I was more captivated by what you were saying. I just want to say I appreciated it. It is wonderfully well laid out and quite clear, and there are recommendations at the end of it, and I can assure you we will crib from it with abandon.

Curt?

STATEMENT OF MR. CURTIS DECKER

MR. DECKER: I am Curt Decker, and I am Executive Director of the National Association of Protection and Advocacy Systems, which are federally funded and federally created advocacy agencies throughout the country to represent people with disabilities.

At the present time we have some limited jurisdiction, so we are not representing all people with disabilities yet, but in that capacity we do in many of our jurisdictions represent people with HIV disease.

I also, as you said, chair the Civil Rights Task Force of the National Organizations Responding to AIDS. I think by now you have probably seen my colleagues in their various capacities as co-chairs before you, and now it's our turn.

I have to say that the task force has ably been co-chaired by Hy Feldbloom, who has deserted me in that job, and we'll soon be having another person coming onboard I hope.

We ar also at the point in time in the discussion, I guess, where you will start to hear some redundancies and reiterations of what has already been said, but given the importance of the issue I think that's probably not inappropriate.

I want to talk a little bit about the ADA in terms of its larger context of HIV disease as part of the disability community. I think you all know that passing the ADA, apart from the great joy that there was in that community, really said a great deal I think about how you move something like antidiscrimination legislation through the Congress, in terms of joining with a larger umbrella set of organizations to move this kind of issue forward. And the ADA, probably one of the few times in the history of the disability community, showed what could happen when all disability groups came together and decided to take a uniform approach--and that was difficult at times. There was no question at various points in that very arduous process, through all the subcommittees and full committees, it would have been very easy to slice off some of the more unpopular disabilities and move forward much quicker. But it is important to remember, I think, that the general disability community was adamant about not letting that happen, because I think there is an understanding in the disability community that at any given time in history there is a particular disability that is unpopular and that many of those disability groups could see what was happening around HIV disease as something they experienced 10 or 20 years ago.

There was a time when people thought mental retardation was contagious. So that kind of approach held us together, and I think there was even a moment at one point in some White House negotiations around the Chapman amendment in particular, the HIV food handler, there was an offer to move the bill forward if we took out that provision. And the feeling was that we'd rather not have a bill at all if that happened. I think that is an important concept to remember as we try to deal with these issues that are facing us now and that are going to be coming down the road in the long term.

To sort of counter that argument, I think within a few months later, we saw what happens when the disability community splits, and when we got into the appropriations process we had the opposite--a real battle between groups fighting over dollars--and while that might be understandable given how important money is and how it drives our whole system, when that happened, all of that good work that brought people together sent us off in different directions, and we're still going through a healing process, and unfortunately that may get worse before it gets better given the sad state of affairs in terms of appropriations.

But it also says something about the fact that the history of disability law really provided a very good base for dealing with the issues raised by HIV disease, and I think you have already heard that with 504 and the subsequent Arline case and then the Department of Justice memo, really, for those of us in the disability community, it was kind of a reaffirmation that that network of reasonable accommodation based on a qualified handicapped individual works and is something that we need to preserve and keep in place, not only for HIV disease but whatever the next issue is going to be when it comes down the pike. There has got to be that marriage between the two organizations.

It has taken a lot of work, frankly, to show the traditional disability community, for lack of a better description, that they needed to be concerned about HIV disease, and vice versa. I think it is important for the AIDS community to understand that a great deal of the protections that they can enjoy will come by working closely with the disability community.

In particular I think we have to remain vigilant around this early implementation stage of the ADA. There are still many concepts and terms in the ADA that are undefined. I think the common knowledge is that many of the definitions about readily achievable, undue burden, will probably be played out on HIV issues, that, and probably issues of mental health. Those are the two controversial disability populations contained in the ADA. So it is going to be very important to make sure that as those cases come forward, not only will they impact on people with HIV disease, but they are going to drive the entire interpretive body of law around ADA.

I think the message for the Commission, as well as other disability organizations, is to remain vigilant, to make sure that as the regulations--as you know, both EEOC and Department of Justice issued proposed regulations; those comments were due in April, and we are now awaiting the final regulations--they are going to be an important framework for the eventual enforcement as the various time lines click in. I think Bill was right that it is not only staggered, but it is staggering. And I don't think a lot of people yet know what we have done. As those time lines come into effect, I think there are a lot of people who will be surprised at the breadth and the depth of this law notwithstanding, I think, Bill's very good delineation of the limitations of the act.

And again, we are concerned that when that realization hits, there are going to be many efforts to overturn both the law, the regulations and whatever court cases come down, and again, I think this Commission is going to play an important role in making sure that we hold the ground that we have gained and build upon it and not recede.

In terms of implementation, I am concerned that there seems to be some sense that this is a self-implementing law and that people could just roll up to the nearest 7-Eleven and say, "I'm here, let me in; the ADA says so." This is a very complex law, and it is going to have some very difficult moments in terms of trying to work out exactly what these various terms mean and how they operate throughout the country in a variety of settings.

It is going to be very important to build, as Bill said, a very comprehensive legal advocacy network to make sure that people have access to legal representation, that the cases that come forward that are going to drive the interpretation come, if you will, to the right people. I think many of the people around this table live in fear that the determinative case is going to land in the lap of one of my colleague private attorneys, who sails up to the Supreme Court, and we run down the road chasing them, trying to convince them that they really need to listen to some of the experts in the field about what impact this is going to have. And I think a comprehensive network can help alleviate some of those possibilities, although not entirely.

Unfortunately, right now I think there is a patchwork of that network. There are certainly CBOs, ASOs, who have worked hard to build a legal component within their agencies. Certainly the ACLU has got its branches. My organization is trying to meet some of the needs. There are law clinics. But it is very spotty, it is patchy, and there are great gaps in the comprehensive services.

We need to support those existing organizations and also look at what is out there. There are several things on the horizon that I think the Commission should be aware of and be actively involved in.

I think the first level is technical assistance, getting information and education out to the community about what the law says, what it doesn't say, and how it could implement itself.

At the moment, there is on the street recently published a notice of priorities from the National Institute on Disability and Rehabilitation Research that is putting $5 million out for technical assistance training in ADA.

Unfortunately, I think, they have taken a concept of regional centers. There will be ten regional centers under their proposal that will provide the technical assistance and training to the field, both the business community and to consumers.

We tried to convince them that that had real difficulties for certain disabilities, especially HIV disease, in trying to develop ten centers, ten levels of expertise, to try to coordinate that, to make sure there is a consistent message, but unfortunately given the report language, that and the appropriations bill, that is going to go forward. But there is going to be some initial funding for the development of materials and information on ADA implementation, and it is very important that groups with AIDS expertise apply for that money and get it so that we can develop a good body of information on how the ADA impacts people with HIV disease. And it is also going to mean watching the development of these ten centers and trying to make these into something worthwhile.

We prefer to have some centers of excellence where there would be one group that would focus on HIV disease and mental health, et cetera, but it doesn't look like that is going to happen.

There is a priority out, comments are due in 30 days, and I hope the Commission will comment on those priorities. I brought copies of that announcement.

There is another actual grant award out from HRSA. Under the Ryan White Care Bill, there are going to be some demonstration programs to demonstrate legal advocacy for people with AIDS. We need to get that word out.

Thirdly, there is a priority out from the Department of Education on setting up a new Protection and Advocacy program for people with severe disabilities, including people with HIV disease, and those grants will be set up this summer to try to expand the network at the local level.

Let me just finish up by talking a little bit about again what I think the Commission needs to focus on.

Unfortunately--and I know it is frustrating for you--but the public relations aspects of this are still adamant. You are only as good as your last newspaper article. There was one this morning; that means you literally need to start again today, re-educating the public about some of these issues, especially around the testing of health care workers.

We need to continue to realize the connection between the disability community and the AIDS community and strengthen that community.

We need to export the expansion of these legal services at the local level. While the administrative agencies certainly have the mandate to enforce these bills, most people don't want to go through that kind of lengthy administrative procedure. They want quick help, and they don't have the time or the energy to pursue those lengthy things. They want a lawyer in their home town who can hopefully mediate quickly and give them the benefits of the ADA and the other legal protections that exist.

Lastly, I would be remiss if I didn't mention another area that I think is going to be a long-term problem, and that is the whole issue of HIV infection in people with mental disabilities, both those with mental retardation and mental illness, especially that population that is in large congregate living arrangements who are not going to have access to education, to care and to protection.

Thank you.

MR. DALTON: Thank you.

Katherine?

STATEMENT OF MS. KATHERINE O'NEILL

MS. O'NEILL: I am Katherine, otherwise known as "Kate" or "Katie", O'Neill, depending on who likes that name better, and I am here in my guise as the HIV/AIDS Policy Director and also our Legal Services Director at the Legal Action Center of New York City. We are a nonprofit law firm who has been in existence for almost 20 years, during the early years of which Harlon Dalton worked there, and we for the first ten years of our existence focused, among other things, on the problems that people with histories of drug and alcohol abuse or addiction had in obtaining employment and other basic benefits.

When the HIV epidemic hit those people who had history of drug use in their families, we also became very involved in the policy and the legal problems that are created by the association between those two epidemics, and we are funded to provide direct legal services to people with HIV or AIDS as a direct or indirect result of drug abuse as well as to do policy work on the national and State level concerning those two things.

I have a couple of points to make. One of them is that while the ADA in most respects was praiseworthy as a stunning example of extending protections against discrimination to people with disabilities, there was one area in which civil rights protections were contracted by the ADA, and that is in the area of people who have problems with drug or alcohol dependency.

During the 1970's, Federal laws were enacted, including the Rehabilitation Act, that for the first time recognized drug and alcohol dependency as health conditions and also for legal purposes, handicaps, meriting protection against discrimination on that basis.

What happened with the ADA was that the Rehabilitation Act, the major Federal law, which had achieved some protections for people with current and also former drug abuse problems, and the ADA were both written so as to exclude from the protection of the discrimination provisions individuals who currently engage in the illegal use of drugs.

The ADA's provisions do say that persons who have participated in drug treatment programs and are no longer illegally using drugs, persons who are currently participating in treatment programs and are not illegally using drugs, and persons who are erroneously regarded, for instance, by a wrong drug test as persons who use illegal drugs, those persons are protected still. But what the ADA and the Rehabilitation Act now do is to protect no one as a disabled person if that person is currently engaging in the illegal use of drugs.

This has a major impact on the coverage and the protection of people who are affected by HIV as a result of drug use. I looked at the CDC's surveillance statistics--they are already out-of-date, but I had the ones for May of 1991 in front of me--52,000 people, if you include both those whose risk factor is IV drug use and those whose risk factors are both engaging in homosexual or bisexual behavior and IV drug use, the combination of those two equal 52,000 of those persons who have been diagnosed with AIDS out of 175,000--I heard last night it was 179,000--people now diagnosed with AIDS. A very major chunk of persons with HIV in the United States are persons who not only have had histories of drug abuse and now are recovered, but have HIV infection, but also people who either have serious drug dependencies or who continue to use on a periodic basis drugs and also are diagnosed with HIV.

One of the recommendations that we would have for the Commission is to understand that protections against discrimination which exclude a very major part of the people who are affected by HIV are not going to save from discriminatory actions lots and lots of people who are the concern of those who are providing services to persons with HIV or AIDS.

The contraction of protections for people with current drug use problems in the ADA is a reflection of something else that has an impact on how we deal with the HIV epidemic. It is a reflection of the continuing schizophrenia of the United States and its policymakers about whether to accord as a major health problem credence to addiction and to treat addiction as a major health problem.

It is also reflective of what during the last ten years, really, as the HIV epidemic has been unfolding, the unfolding of an increasingly punitive attitude toward people who are using drugs, and the combination of "This is not a health problem" and "We will punish those people for use" and the failure to recognize that use when it is use in connection with dependency is a major problem that merits treatment and also merits being fairly treated, all of that combination I think results in our standing in 1991 with having only partially solved, even on a statutory basis, the difficulties of discrimination and exclusion of people from absolutely essential services.

There are specific implementation problem with the ADA, even with its reduced coverage of a major part of the people in the United States who are affected by HIV. The Legal Action Center has been one of the only organizations in the country which for 20 years has fought to accord fair treatment in health care and in employment to people who have past histories, since overcome, of drug use, and the combination of having HIV and having a past history of drug use is a lethal combination and will continue to be a lethal combination in terms of people's access not only to employment, but also to health care and other vital social services.

One of the things that the ADA did was to say even though we are going to exclude from the definition of individuals with disabilities those people who are currently using drugs, the ADA does have a provision that says however, persons shall not be denied health services or services made in connection with drug rehabilitation if they are currently engaging in the illegal use of drugs and if they are otherwise entitled to those services.

So there is some hope that the ADA will accord protections and help people who are currently using drugs gain access to certain vital health services including those that are needed, for instance, if they are being diagnosed or tested for HIV. However, the problem is that in terms of implementation, what health services people will still continue to have access to even though they are currently using drugs and what services there are in connection with drug rehabilitation that are going to continue to be made available to current drug users is not altogether clear.

For instance, are vocational rehabilitation services, which are absolutely key to helping people recover from addictions, going to be shut to persons with current drug problems, including persons in treatment programs who, because addiction is a periodic and chronic and progressive disease, are probably going to be involved in relapse every once in a while; are those services going to be shut to people who are in treatment programs but nonetheless have not stopped altogether using drugs? It is not clear.

It is not clear what the impact of the exclusion of current drug users is going to be on social services that are also vital to the recovery of persons with dual problems of addiction and/or HIV infection.

I think that one of the difficulties with the lack of clarity, even though the Congress has said for certain health services, we'll let drug users have access to them, is that many traditional health and social service providers are reluctant to provide care to persons who have active drug problems, and they will fight the expansion of the definition of health services and services done in connection with rehabilitation to the extent possible.

Another problem with implementation in terms of the population that we provide services to in this area is that health providers and social service providers who say we don't want to serve you because you use drugs really have the upper hand. To educate persons that they do have a right to those services, to empower them to find the advocates that are needed in order to overcome the resistance of many social service providers to treating that population, and to give the advocates the wherewithal to fight in terms of litigation and other areas to open up needed services is a real challenge for which there are not very many organizations around that are funded or capable of responding to that challenge.

Another problem with the limitations imposed by the ADA is that--and I mentioned this before--there are an increasing number of advocates who provide legal services and other work on behalf of persons who are affected by HIV, but there continues to be a dearth of people who are knowledgeable and committed to dealing with individuals and providing services to those who are affected by both drug use and HIV. And unless funding and education is done about both addiction and HIV, and those organizations are empowered to help, then the fact that there are even reduced remedies and protections is going to mean nothing in reality.

The last point I would like to make quickly about the ADA and its protections against discrimination is this. Many of the people to whom we provide services in our HIV Legal Services Projects are not concerned about discrimination and overcoming discrimination as the major barrier to their getting along with life and maintaining the quality of their lives. Major concerns of persons who have HIV infection attributable directly or indirectly to drug use have more to do with, for instance, how the foster care system is going to treat them; what is going to happen with mandatory screening proposals for newborn testing; what kind of access to care and who makes decisions about care for women who, for instance, have HIV infection as a result of drug use and their families; what kind of help is going to be given to those people who have been hit by both the drug and HIV epidemics and who have to make plans for the care of their children or for the care of family members. None of those things are touched by the national discrimination law, and all of those are absolutely essential issues which have major civil rights implications that are faced by the population that we deal with.

The last thing that I would like to say is--and Nan mentioned this before--the epidemic is shifting. To give you an example of how the face of the epidemic looks right now, let me just tell you the sorts of people that we help in our HIV services project, which is direct to people who have HIV as a direct or indirect result of drug use.

Over two-thirds of our clients are African American or Latino. In fact, 40 percent of our clients are Latino. Forty-seven percent of our clients are women and their families, meaning children and the collateral relatives of their children. And as I said before, many of their concerns are not with employment discrimination but with access to basic services.

The last thing I'd like to say is that the ADA's provision that even current illegal drug users may be given access to health care and services in connection with drug rehabilitation also provides that they can have that access even though they are using drugs if they are otherwise entitled to those services. The problems are that people do not necessarily have entitlements to critical services like access to clinical trials and so on.

So the ADA is really wonderful, but it has a major gap in it, and even for those people who it does protect in the community affected by both the drug and HIV epidemics, the battles to overcome both resistance and the legal barriers I think will continue into the 1990's as the epidemic shifts into the 1990's to more and more people who are affected by HIV as a result of the drug epidemic.

Thank you.

MR. DALTON: Thanks, Katie.

The original plan was to allow the panelists on the outside of the circle to weigh in at this point. However, I think you are all clever enough to figure out a way to sneak whatever you have to say about the ADA into your remarks about HIV in the 1990's, and I guess I'd rather like to take the next 10, 15 minutes for commissioners to direct questions-

-and actually, if you all want to answer the questions, that's one way to sneak in now.

Are there questions? Eunice?

MS. DIAZ: Coming from a long line of years of experience in the physical rehabilitation field, I wonder, Mr. Rubenstein, as you spoke, whether or not the challenges that are going to be faced by individuals trying to seek protection under ADA for reasons related to mental impairment are going to be much harder to document, particularly in the workplace--and I'm thinking of the standards that Dr. Hunter talked about, of reasonable accommodation and trying to establish that the person should be maintained in a certain occupation, will be much harder to determine legally.

I think in the area of physical disabilities and rehabilitation, it is much easier. It is fairly visible, and there is generally some consensus as to what might be done. But when you talk about mental disability or impairment, that's just a grey hole in terms of what I think we're going to be faced with in trying to implement ADA.

I just wanted your comments on that, if you would, please.

MR. RUBENSTEIN: Well, I think it is an interesting point, and it gets to the fact that some of the comments I was making about the limitations of the ADA, both how it will play out in practice and what it will cover, don't just apply to people with HIV disease; it applies to all people with disabilities who are getting this kind of protection in the private workplace for the first time.

So I think you are correct in pointing out that another area where that may come up is with regard to people with mental impairment.

Now, the thing to remember is again that the substantive provisions in the ADA to derive from Section 504, the Rehabilitation Act, so there has been some experience in dealing with this in the past, so you are not writing on a completely blank slate, and whatever is there will come out again.

The third point I would make is that in terms of burden of proof and proving a discrimination case like that, you may be correct that in a given case it may be very difficult to document in the same way or to talk about what a reasonable accommodation is with regard to mental impairment; it may be different than raising the level of a desk for someone in a wheelchair.

So I think you raise a good issue, and I concur that these are again an example of how we'll have to wait and see what the experience is under this.

MR. DECKER: Actually, I'd just like to comment--we've been trying to search out what is available in terms of reasonable accommodation for people with mental disabilities, and it is nonexistent. Despite 17 years of 504 history, there is very little in the literature or in the law about what is a reasonable accommodation for people who have cyclical kinds of disabilities. And frankly, that is what employers seem to be the most concerned about at the moment, is what are their liabilities in terms of hiring someone with a mental disability and keeping them.

So we've got a lot to do even before implementation so that we can prepare the business community on how to deal with the chronically mentally ill, and to the extent that there will be people with HIV infection who have dementia, they will fit in that category.

MS. DIAZ: Thank you.

DR. ROGERS: First a comment, then a question. This has been very helpful.

Ms. Hunter, I thought your comments on significant risk were refreshing. I hope we have before us or on hand precisely what that definition is now, because we're going to need to use it in the fights that you have mentioned.

I have been sitting here thinking, Mr. Decker and Ms. O'Neill--and I know what the Commission posture should be--but Katie, you are saying 30 percent of those who are HIV-infected are really excluded by virtue of their drug use from the ADA provisions. I know what we should do; on the other hand, I heard your caution, Mr. Decker, in terms of when some of our public see how liberal that law really is, we're going to have a hell of a lot more battles. And I guess my debate within my own head is should we surface this one right now in terms of saying let those drug users in, which will start the battle much earlier than if we wait to have everybody find out what the battle is going to be about.

What do we do as a Commission here?

MS. O'NEILL: If you surface the debate, you will be hit in the face, and that will get nobody anywhere, I think. I think the Commission could do a couple of things. One of them is to insist on people understanding and complying with those portions of the ADA that do accord protections to persons who are recovering from drug use. A number of people with HIV infection, of course, have stopped using drugs.

But it is very difficult to make people understand that there is a distinction between current drug use and a recovering drug user. So to the extent the Commission can say do not forget this population, and do not let people get away with forgetting or ignoring the population of recovering drug users, I think you will have done a great deal.

I think the other thing the Commission can do is say that discrimination laws that are in place right now are a start; they will help many people if they are fully implemented and enforced. But we must be aware that there are other civil rights and access to care issues which have an impact on the drug using population, and we must as a Nation develop policies that do not run roughshod over basic civil rights of persons who are currently using drugs and other areas--such as, for instance, making decisions about foster care/adoption, helping people make plans for families. I think that that is absolutely key as well.

DR. ROGERS: Mr. Decker, I hope you will comment as well.

MR. DECKER: Well, I agree that focusing the debate on that particular issue is probably not a good idea. There is an ADA industry growing out there, and a lot of our colleagues are making a great deal of money offering their "assistance" to the business community about what ADA means to you and how you can avoid it. So there really needs to be a consistent, I think, countervailing public relations campaign that lowers the level of hysteria.

I do think that despite the breadth of the law, a good 80-90 percent of the reasonable accommodation that we are talking about is low cost, common sense. We often use the term "codifying courtesy" through the lobbying efforts. That's really what the majority of it is going to be in terms of accommodating people with disabilities, including HIV disease. And there are going to be some tough ones on the fringes. And I think the Commission can play a real role in getting people ready for the fact that this is not going to be a big deal for the great majority of people with HIV infection.

MR. DALTON: I can't help but comment--Barry Sullivan, I'm glad you are here to represent those sleazy private attorneys who are going to get the first case in the Supreme Court and are probably also the ones who are making the money telling employers how to avoid ADA--but you'll get your chance later.

[Laughter.]

MR. SULLIVAN: I want to make it plain right now that I represent only the first-class sleazy lawyers.

[Laughter.]

MR. DALTON: Fair enough.

Don Goldman.

MR. GOLDMAN: Thank you.

I just want to say it's a pleasure to have all of you here. I particularly want to thank Nan, who has been so terrific over the years both with the ACLU and then still continuing on now. The publications that you continue to produce and that Lambda continues to produce are just absolutely marvelous tools for the entire community, and I want to express the appreciation of I think all of us out there who really get to know what's going on often first from you, particularly in terms of many of the legal and sociological issues that evolve.

And Mr. Decker, I want to thank you very much also, not only for your hospitality to us on a personal level in Baltimore when we met there, but also for the fine and caring assistance that you and your agencies have provided for persons with hemophilia affected by AIDS and HIV infection across the country, and as well as to the ACLU cooperating lawyers who have done the same in many instances.

That's all.

MR. DALTON: Irwin.

MR. PERNICK: Actually, I want to share Don Goldman's and Harlon Dalton's view on having all of you here and listening to your presentations. I think for the first time in a long time Don and perhaps I feel comfortable because we are surrounded by more attorneys than we are by doctors and other health care professionals.

Ms. Hunter--and I also share David Rogers' view on your presentation and the need to help us definitionally--but in setting up the early part of your presentation discussing significant risk and objective medical evidence and, on the other hand, informed consent, you must help us appear to advocate the protection of civil rights at both sides of that particular dilemma. How do we appear to protect one side's civil rights without appearing to abridge the other side's civil rights?

I think you probably know what I mean. You could take the classic example of the surgeon or the dentist against--and it has to be against--the patient, because that's the way the issue will be viewed.

MS. HUNTER: Well, I think that is the way the issue is already viewed, and I think to an unfortunate and distorted extent.

The point that I was trying to make is that I think the best way to approach this overall, and I think perhaps the only way that has any hope of trying to intervene in the public discussion, which I think has become quite hysterical, is to try and ground it in risk assessment--what is the risk to the patient, what is the risk to the doctor.

I'm not suggesting that those questions not be asked; that is not my suggestion at all. My suggestion is that those questions be asked in a way that is placed in context and that is grounded in some kind of real attempt to assess that risk in the same way we assess other risks in life, that we assess the risk from both sides of that, from any side of that. I'm not suggesting at all that I think either patients or physicians or other health care workers--that their concerns and their needs for safety should be disparaged. I don't mean to suggest that at all, but I do think we have to resist the impulse to letting a kind of hysteria, which I think it has become, and an over-reaction to the suggestion that there can be any risk distort what the society's assessment of risk is.

There are many risks, for example, in surgery; there are many risks in the health care setting. I think that one of the most important protections this area, as is often the case in questions of law dealing with any kind of equitable principles, is to force the law and policymakers to consider these risks in the same kinds of terms as other comparable risk--what is a comparable risk to HIV transmission in that setting? I suggest to you that the comparable risks are infinitesimal.

We can't ignore, I think, the tenor of public debate, and the tenor of public debate has been shaped by an instance of, in this case, the transmission from the health care worker to a patient, by one health care office in Florida out of thousands and perhaps millions of instances of surgery, much less other less invasive procedures, much less other dental practices, which have occurred in this country over the last ten years, and there has been I think a wild distortion of what the risk is.

So my invocation of you actually is to the general principle. One reason for that is that frankly, I think if the general principle fails to hold here, it will fail to hold in the future in other situations. It is coming up now very acutely in the context of the health care setting, whether the risk is to health care workers or whether the risk if rom the health care workers to patients. But if significant risk, if that legal principle becomes so eviscerated that it is essentially toothless, then it will be toothless in years to come for other settings as well.

I think that we as a society have gone through a process--and this is why I tried to describe some of the school children cases--we went through a process of framing those cases in a way that did put it in the context of real risk, and I think we have to go through that same process again with this issue, and I think it is more difficult for a variety of reasons, but I think we have to insist on that process and that we have to be honest about where that process takes us. But I think we have to insist on an adherence to that same standard.

MR. PERNICK: Thank you very much. Just one additional point. I absolutely agree with you, but remember in a civil rights context we are looking at the rights of the individual against the actions of society, and in this case we are almost asking each individual in the Nation to accept more risk than a lot are willing to accept individually.

MS. HUNTER: Well, I think that was true for school children as well.

MR. DALTON: Tom first, and then Bill.

MR. STODDARD: Yes, if I could respond to the question, your question was fascinating to me because I think it highlights one of the great difficulties this society has in dealing with all of the civil rights and civil liberties questions related to people with HIV. Indeed, it highlights for me the problems that society has in dealing with civil rights questions generally.

The premise behind your question, I think, is that civil rights essentially amount to a zero sum game, that if somebody gets more rights, somebody else loses rights. And you may not have intended to say that, but I think that is often the popular conception about civil rights, and it is a conception promoted by Phil Donahue and Oprah Winfrey, the "Crossfire" show, lawyers who like to deal with these issues in a confrontational way, and a variety of other factors.

And there are certain members of Congress who propose in an implicit way about civil rights questions that if somebody gets more rights, somebody else loses rights, and therefore it is a zero sum game.

I would like to suggest that we try whenever that idea is put forward, particularly with regard to HIV disease, that we try to resist that formulation because framing the issue in that way automatically leads to a certain kind of answer that is not healthy. And I would suggest that giving civil rights to any group of people enhances everybody's rights because it enhances the entire tenor of the society, and that's true with people with HIV disease, too.

There was a time in this country 100 years ago when we dealt very primitively, very punitively, and very unfairly with illnesses and people with illnesses, and we did it because we had no conception of civil rights, and we didn't really care about the individuals involved. We just dealt with the entity of society as an organism. That is extremely unhealthy, and one of the great benefits of the civil rights revolution of the past 50 years has been that we have moved away from that; one of the reasons, I think, why we have dealt more responsibly as a culture with some of the civil liberties questions regarding HIV disease.

With regard to health care workers, for example, I don't think it is a question of who wins, the health care worker on the one side or the patient on the other. The issue I think ultimately ought to be infection control. Infection control is probably the source of the difficulty with the dentist in Florida, although the public doesn't know that, and it is not talked about very much, and it is the one issue that we could deal with generically to reduce transmission of HIV and other illnesses if we chose to do so. But frankly, the talk show hosts make it hard for us to reframe that question, and to some degree we simply accept their formulation and argue on their terms--and I have been guilty of it, too; I think we all have.

So I would suggest that we try to reframe those issues and that we recognize that all of us, the Commission in particular, have an extraordinarily important public education function to serve.

I love the ADA, although as Katie pointed out, it has limitations and exceptions that are unfair, and as Bill pointed out, it hasn't been properly implemented and may not be properly implemented--but even if it were, it wouldn't make any difference in the world if all the money of the Federal Government were used to implement it if Americans wish to discriminate.

The Civil Rights Act of 1964 did not end overnight race discrimination or gender discrimination. We know that. In fact, those issues may be more difficult to resolve now than they were 20 years ago.

The ADA will not resolve disability discrimination. I say that in part because of the New England Journal of Medicine piece of a month ago, that almost seemed to imply that because we now have the ADA and antidiscrimination protections, we shouldn't worry about testing people against their consent because there will be no implications to people being HIV-positive. Well, that's nonsense; we know that's nonsense.

So with all of the good things that the ADA and comparable State laws provide, we have to teach the American people, particularly those who lead them, about these issues, and we have to make them believe that the risks really are insignificant, because they are, and we have to make them understand why discrimination is wrong. More than anything else, we have to make them believe that civil liberties and public health go hand-in-hand. You cannot treat people disrespectfully and with hostility and confrontationally and expect them to join in a fight to preserve their health and the health of other people.

That's a sermon, and I apologize.

MR. DALTON: I was thinking it was sort of a nice benediction--it would have come at 12:00, but that's okay.

MR. ROGERS: Should we give you another half an hour, Mr. Stoddard?

[Laughter.]

MR. DALTON: I am actually quite rarely proud of being a lawyer, but for this brief moment I must say--

MR. GOLDMAN: Harlon, speak for yourself.

DR. OSBORN: And Harlon, I have rarely been so frightened of being a doctor.

[Laughter.]

MR. DALTON: Let's take a break. One brief comment. Curt at one point suggested that we have entered the phase where the conversation would become redundant. Happily, it did not, and I want to thank the panelists for that. I also want to suggest that that's a model for those people to follow after the break.

After the break, the folks who have been on the outside will take those seats, and the folks who were there will be around the outside, and people will have a brief amount of time to enlighten us with respect to civil rights issues in the Nineties.

But let's take a 15-minute break.

[Short break.]

MR. DALTON: Before we pick up with the next panel, Don Goldman has something he wants to say.

MR. GOLDMAN: Some of you have pointed out a number of things, and one of the questions and issues that has of course concerned this discrimination has been regarding the immigration issues. The Commission meeting yesterday decided that looking at it from an historical perspective, namely, that in December of last year the Commission issued a statement and held a press conference dealing with the issue and making certain recommendations, that among those recommendations were that these issues ought to be decided on public health grounds and not on political and grounds of myth, prejudice and social stigmatization. We recommended that the law be changed to allow that kind of perspective to be viewed rather than the legislative one.

We recommended that the Public Health Service conduct an examination and make those determinations based upon medical standards and epidemiology.

All of those things happened in accordance with our recommendations, and finally, in January of this year Secretary Sullivan promulgated regulations based upon those standards, and we should have thought, and we did think, and we hoped and assumed that that ended the issue. Our recommendations had been fulfilled, the recommendations which I think are consistent with all of you, and that should have been the end of it. It should have been the end of it on grounds of right as well.

Unfortunately, that does not appear to be the end of it, and therefore in some cases, some new questions and issues have been raised, the merits of which are questionable, and in any event the Commission has decided that it will continue to examine that issue. It will solicit some additional perspectives on those issues and will be issuing a further statement on the issue during the week following July 4th weekend. We will be issuing a further statement at some point during that week in some form or format.

So we will continue to into the issue. We have continued to do so. We have been in contact during the course of the past few months and years, both legislatively during that process as well as with Secretary Sullivan, who was a colleague of ours on the Commission during the regulatory process as well. I thought particularly that this audience here is so interested in that issue as it is, that it ought to know what we have decided to do, and a formal announcement will be made as to what we plan to do and how we are going to proceed.

Thank you.

MR. DALTON: Okay.

The next panel is entitled "Civil Rights and the HIV Epidemic", which is pretty open. We have invited seven quite knowledgeable people here to give their sense of what is ahead in the next decade with respect to civil rights.

Since there are seven of you, it means a little less air time per person, and I'd like you to try to keep it to five minutes, because as you saw at the end of the last panel, sometimes life gets most interesting when there is exchange back and forth. And just as Tom decided to take over the last panel, these other people are going to take over yours if you give them the chance--I'm teasing, Tom--but we can have much more of a roundtable.

But we do want to give each of you a chance to give us the high points of your sense of where we are headed in the Nineties.

I think everybody here, at least who wants one, has an agenda, and so it has your names and your affiliations; if you want to say more by way of introduction, that's fine.

I did want to introduce Carlos Santistevan, who didn't make the typed witness, but he is with People of Color Against AIDS here in Denver and is involved in the Chicano outreach.

MR. SANTISTEVAN: I am a community outreach worker with People of Color Consortium Against AIDS.

MR. DALTON: Okay.

I'd like to start on the left, really as a way of sort of forcing Phillip Wiley to start out. I spoke to him during the break, and I'm thinking that some of the things he has to say may help to frame the issues that other people focus on. So that's why I want him to go first.

Phillip, welcome.

STATEMENT OF MR. PHILLIP WILEY

MR. WILEY: Thank you, and it is an honor to be here.

I hope to address this from several different perspectives, but I'll start out by saying I am an HIV challenged individual. I am why you are here. And what I see still scares me. I think Nan said it very well, and others said it very well--as we move into the Nineties and the face of the epidemic changes, we will see less and less people involved in this because of who it is affecting now.

Living in small-town America--it is wonderful to live in New York, it is wonderful to live in L.A., where you have strong supportive organizations that are there to help you and back you--but when you live in Tulsa, Oklahoma--when I got the phone call to come, for instance, they asked me "Do you live on a reservation?"

[Laughter.]

MR. WILEY: So we have to deal with that, but it is scary when I go out and I see what is available, and then I go home and have to deal with the realities, the realities being that yes, it's wonderful to have these laws that we talk about, but in actuality they don't work; they are not working.

I lost my job because of my diagnosis. I am not the only one. It is hard to find lawyers, doctors, who will accept HIV-challenged individuals. I did a survey in Tulsa, where I phoned 175 dentists in the City of Tulsa to ask them if they would work with an HIV-challenged individual, and I was given things from "My wife won't let me," to "Yes, I'll do it, but I'll have to charge extra."

There was an incident where an individual was going to have open heart surgery and was given an HIV test without his consent and told if the test came back positive, the doctor would not operate because "you are going to die anyway."

These things still go on despite the fact that we have laws that say you cannot discriminate. Just because we say you cannot doesn't mean that we don't. It does exist. What I hope to see happen is empowerment of the HIV-challenged individual in the Nineties. If we empower HIV-challenged individuals, they will become your best educators, they will become the greatest advocates for any type of civil rights. If I feel good about myself, then I'm not going to put anyone else at risk. But if you are constantly telling me that I'm going to die and I'm no good, and all those other negative things, instead of helping me become something that is good, then I'm going to remain in that state.

So what I would like to see this Commission do is somehow help those individuals who are HIV-challenged to become more positive about themselves. How you do it, I don't know, but to me it is important.

I'll stop there, because I don't have a lot to say.

MR. DALTON: I think you've said a lot. Thank you. Tom?

STATEMENT OF MR. THOMAS B. STODDARD

MR. STODDARD: Thank you, Phillip. That was enormously powerful and important because we have to remember that this is about individuals and real people, and not an abstraction, not an intellectual or political exercise. It is also very hard to follow.

I would like to stress that there are hundreds of thousands of people in Phillip's circumstance around the United States, but most of them cannot step forward. They are fighting for their lives, and they cannot also summon the energy at that moment to fight for a lost job or for a lost apartment, and those who can step forward need to be thanked with enormous gratitude, because they speak for so many others.

Those stories are often not heard. I think that is one of the reasons why we have reached a moment of danger, as Nan mentioned at the beginning of her talk, that Americans don't hear these stories enough. If they do hear them, I think most people will care, and their attitudes will change. So we need to constantly bring these stories alive to make the real stories of people with HIV and AIDS visible and audible to Americans.

Harlon instructed us not to be repetitious, and I am going to violate that for just a moment, if I can, because Nan started a discussion that I think needs to be expanded a bit.

Nan mentioned, I think quite rightly, that this is a very perilous moment. Something has happened in the body politic that threatens the way in which this country deals with AIDS and HIV, even assuming we have made progress so far. That is certainly true on the issues of civil rights and civil liberties, putting aside for a moment the issues of medical care, if one could ever attempt to extract them, and one probably shouldn't because they are interrelated.

I have tried to figure out in my own mind why I think this is a perilous moment and why we seem to be revisiting questions that we had hoped had been resolved in an appropriate way earlier.

Some things have to do with certain constants dealing with the HIV epidemic, with the fears that people bring to AIDS and HIV that have never really been alleviated, to certain, frankly, ideologues, some of whom have Federal positions and hold other official posts, who wish to use the AIDS epidemic for reasons that have nothing to do with AIDS or HIV.

Some of it has to do with certain traditions within public health, dealing with past epidemics, that were not particularly well-conceived and in many instances were counterproductive.

What is new now? Well, it may have something to do with the changing epidemiology of AIDS, as Nan alluded to. It might also have something to do, frankly, with medical societies and medical associations. And at the risk of being a bit confrontational or controversial, I want to suggest that I think that is happening to some degree.

Within the past several years, various State medical societies have adopted resolutions promoting the testing without consent of very large categories of people with AIDS and HIV. The first medical society to do this was in Illinois, as far as I can tell. Illinois three years ago adopted a statute that permits doctors to test people for HIV without their knowledge or consent. I believe that was the first statute of its kind, and it was promoted by the Illinois State Medical Society, the entity that represents in name, at least, all of the physicians in the State of Illinois, and similar medical societies in New York and New Jersey in particular have promoted similar measures without any understanding as to what those proposals will do to the real lives of people.

That is a new and very ominous development. It greatly affects the way politicians respond to AIDS issues, because doctors are articulate and well-financed, frankly, voices, with degrees from institutions of higher learning, and there must be some way I think, ultimately, if we are going to pass this crisis successfully, to reach medical societies and help ordinary physicians who belong to those societies understand why coercive measures are counterproductive--not just that they are a bad idea from the perspective of civil liberties questions, but they are a bad idea from the perspective of giving help and care to people who need it.

Coercive measures will deny care to people who want to save their lives--putting totally aside the civil liberties questions. And the doctors need to understand that.

How do we, collectively, attempt to address this? I think it is largely a public education question to both a narrow public and a large public. The narrow public is the public of doctors and physicians, who are increasingly vocal on this issue. The larger public is, of course, the American people generally.

I would suggest that there is one central message that all of us should try to communicate, and it is essentially this--actually, Phillip said this better than I did just a moment ago, so it is hard for me to rephrase it--that people who have HIV are fighting for their lives, and they must be given an image of themselves and of the world that allows them to fight. Without that sense of volition and will to survive, those individuals will not survive.

Testing people without consent, or treating people disrespectfully, or denying them services they are otherwise entitled to, or telling them that their names will be reported to health officials and kept on permanent record works against that effort to give people the will to fight.

In other words, we have to somehow put the emphasis on the issue of volition, why volition is central to the fight against AIDS and why coercive measures undermine the issue of volition.

Those people who put forward testing without consent, who would deny careers to health care workers who are HIV positive, who would require that the names of all HIV positive people be reported to individuals, do not really understand the circumstances of people with HIV, do not have the proper understanding, I think, of human motivation and the role it plays in this epidemic, and therefore do not understand that these issues really do have to do ultimately with whether people are able to save their lives. We have to get that message out--putting aside for a moment the civil liberties questions--I say that with great pause; I work for the Civil Liberties Union, and I am a civil libertarian--but the civil liberties arguments in this context frankly are not political persuasive. We need to help people understand that it is an issue of public health and the health of everybody.

I think I'll stop at that point.

MR. DALTON: Thank you, Tom. If you did violate my directive, I am quite pleased that you did.

The next speaker is Vada Kyle-Holmes.

STATEMENT OF MS. VADA KYLE-HOLMES

MS. KYLE-HOLMES: Thank you, and thank you for having me participate here today. I am Vada Kyle-Holmes, the Regional Manager of the Office for Civil Rights in the Department of Health and Human Services here in Region VIII.

You have heard other speakers talk about Section 504, and it is our responsibility in enforcing Section 504, and I just want to comment in the brief time that I have about some of the issues that we have seen. You have heard about them already, so I'll be a little repetitive.

But just looking at and thinking about the complaints that have come before us, I would put them in two categories--employment and access to health care. Those have been the major types of complaints. And you know at the Federal level, in HHS, we have been looking at all kinds of health care facilities, hospitals, nursing homes, social service agencies--all of the agencies that receive money from HHS.

Our complaints have been about employment starting from the initial application process on through. We have employers actually screening out persons by asking certain kinds of questions on the application that really are in violation of 504, so that often persons who are perceived as having AIDS don't get into the workplace, and they are screened out right there. This is a big issue.

And then, when it is discovered that persons have AIDS, there is always putting them out of the workplace and putting them on involuntary leave, and all of those things that you hear about.

So there is much work to be done in the employment area.

The other and the greatest issue that I would mention and that we see here in Region VIII, and not only here, but across the country, is denial of admission to nursing homes. We see nursing homes excluding persons who are HIV positive. The nursing homes tell us in those cases that we have investigated, "We don't have space," "We can't isolate them," "Our staff will leave," "The families will move." There is still a lot of fear and hysteria out there that we see.

Some of the issues that I see outside of the health care area--again, that's the biggest area, and hospitals, too, I could tell some stories about if I had the time--but the other issue that I see growing has to do with institutionalized persons, persons who are developmentally disabled or mentally ill. In talking to some of the staff and persons who work with beneficiaries, as we call them, in the DD area, they are concerned about how do we educate our staffs, and what are we doing to prepare for having clients or patients here who are HIV positive or who have AIDS; there are a growing number of children with AIDS, and who is going to take care of them, the whole foster care area.

Many of the areas have been mentioned already, and I won't go into it, but I will come back and say in the health care area, access to health care, all kinds of health care providers--that's the big issue.

MR. DALTON: Thank you.

The next speaker is Barry Sullivan, who is a partner at a large, fancy, massive-wealth-generating law firm in Chicago.

[Laughter.]

MR. DALTON: Barry was actually kind of sitting on the sidelines and stepped into the AIDS fray as really the spearhead for the American Bar Association's efforts to deal with this epidemic.

STATEMENT OF MR. BARRY SULLIVAN

MR. SULLIVAN: Thank you, Harlon.

If I had known that there was an overhead projector, I would have set my card up there.

[Laughter.]

MR. SULLIVAN: I have been the chair of the ABA Committee on AIDS since early 1988. I am also an adjunct professor at Northwestern Law School, where I teach a seminar on AIDS. And in my spare time, as my partners think, I work at the law firm that Harlon alluded to.

I do not consider myself to be an expert on this subject, as are most of the people you are hearing from today. I have had occasion over the last few years, however, to ruminate on the issue of discrimination against persons affected by HIV, and I am happy to be here to share those ruminations with you for what they are worth.

I think first I'd like to make three points. The first is that it seems clear to me that we cannot tolerate invidious discrimination against persons affected by HIV, and I believe that at least on a theoretical level, that is the consensus of our society. I think our society believes now that discrimination is unwise as well as immoral because it deprives society of precious human resources that we desperately need.

Second, it seems to me that we as a society have done reasonably well, at least until recently and at least on a theoretical level, in combatting discrimination against persons affected by HIV. I think that we have done reasonably well for a number of reasons.

First of all, it seems to me that various groups in our society have been willing to stand fast against hysteria, to speak out against ignorance and prejudice and fear, and in general to follow Emerson's exhortation to "common sense and plain dealing".

We have also done relatively well because various credible organs of leadership were able to agree that most fears of contagion are factually unfounded, and thus there was no rational basis for fearing the presence of persons with HIV in the schools, for instance, whether it is teachers or students, or in the workplace or in places of public accommodation.

When courts became involved--and I'm going to have to be a little repetitious here, too, I guess--they were able to conclude that the benefit to be gained by discrimination in these various settings, the potential removal of the risk that others might become infected, was too negligible to counterbalance the cost to society and to the individual, and in other words, that the risk was not significant.

The third point that I would make generally is that it seems to me that, as others have said, we now stand at a perilous crossroad where there is a real possibility that the consensus that I have described is evaporating; that some of those organs of leadership may no longer be capable or willing to provide the leadership that is necessary to overcome hysteria, and most important, that these developments may be occurring for no particularly good reason, from an objective perspective.

There certainly is evidence that some policymakers and courts are retreating from their prior adherence to the viewpoint that we should analyze issues in this area by focusing our cost-benefit analysis, in the jargon of the day, on the risk of transmission. At the same time, there seems to be a trend toward characterizing the risks of transmission as more substantial than the data might otherwise suggest, and therefore toward embracing less modulated responses--that is, calls for routine or universal testing of various kinds, lowering the standards for consent, and so forth, which we earlier deemed to be unreasonable. This seems to me to be particularly true in the health care area, as others have noted.

My basic point today in a nutshell is that the consequences of these developments need to be addressed if we are to ensure that our society is moving in the direction that we think makes sense, rather than simply drifting toward what I fear may be the shoals of reflexive irrationality.

I was going to talk in detail about some cases, but I have had Harlon's invitation to abbreviate that. I would just like to talk about them very briefly, because I think that where we have been is perhaps exemplified by the <u>Chalk</u> case, the teacher who was involuntarily removed from the classroom, and the school was found to have violated Section 504 of the Rehabilitation Act. I think that that is an important case in terms of where we have been because of the emphasis that the court placed in that case on the accumulated body of medical evidence, which showed that Chalk did not pose a significant risk of transmitting the virus in the ordinary school setting. The court also emphatically cautioned against relying on fear and speculation as grounds for justifying discrimination.

The other case that I would mention in that regard that I think also shows where we've been is Doe v. Dalton Elementary School District No. 148, in which a district court in Illinois used the same analysis and reached essentially the same conclusion with respect to a 12 year-old student who had been excluded from school. The court in that case, like the Chalk court, referred to the overwhelming consensus of medical authority, saying that there was no significant risk of transmission of AIDS in a classroom setting. And, as Nan suggested, both of these cases really applied the principle that had been stated in the Arline case.

More recently, there are two cases that I would also like to mention because I think that they perhaps are a bellwether for a different view--Lekelt v. Board of Commissioners of Hospital District No. 1, a 5th Circuit case, involving an HIV positive nurse. I won't go into the facts of that case, but I will say that the court conceded Lekelt's point that the risk of transmission was a relevant factor, but I think chose to place emphasis elsewhere. The court pointedly ignored the remoteness of the possibility that a patient might be infected by a health care worker--at that time, there were no reported cases, I believe--and instead focused on what I deem to be the more inflammatory fact, that there is no known cure for the disease.

In another recent case, Berringer v. the Medical Center at Princeton, the court reasoned in the case of the suspension of a physician who was HIV positive that regardless of how small the risk of transmission, the severity of the potential harm demands that the physician both inform his patients of his HIV status and withdraw from performing any procedure that poses any risk of transmission.

Both of these cases I think are significant for us because they seem to shift the focus from the risk of transmission to the admittedly dreadful consequences of becoming infected.

In my view, this is like focusing on the effects, if I can be parochial, of an uncontrollable fire in the Sears Tower, without also considering the likelihood that such a fire will exist.

Wouldn't this reasoning also lead to mandatory drug and alcohol testing for all health care workers, and what about high blood pressure and heart disease disclosure with respect to surgeons, for instance?

In any event, these cases seem to suggest a trend toward avoiding the harm whatever the cost, even though the chance that the harm will materialize may be minuscule.

These cases do not stand alone. In recent months, we have heard calls from preeminent quarters for routine HIV testing for both patients and health care workers and so forth.

Do these proposals really make sense given what we know about transmission and about the incidence of infection in these populations? Do they make sense in terms of the astronomical testing costs, let alone the social costs? And what are the likely consequences of such policies?

I would allude simply to a couple of surveys, one of which was of persons in the general population nearly half of whom believed that HIV positive physicians should not be allowed to work. I would also allude to the studies which show that many residents and physicians say that if given a choice, they wouldn't care for someone who was HIV positive.

I do not wish to sound alarmist, but I think we need to give more serious and dispassionate consideration to these questions. Otherwise I believe we risk endangering what we have already accomplished in the area of discrimination, and we risk I think most important of all having important decisions made by entities which have a necessarily constricted view of the situation. For that reason, I urge this Commission to take up these issues.

Thank you.

MR. DALTON: Thanks, Barry.

The next speaker is Matt Coles. Matt, a couple of people, knowing you were going to be here, asked me to say hello to you, and I've forgotten who they are, but if someone asks you whether I said it, I did.

STATEMENT OF MR. MATTHEW COLES

MR. COLES: I am Matt Coles. I am a staff lawyer with the American Civil Liberties Union of Northern California, and I think I am here probably because much of the time that I have spent in court litigating over the past three or four years, I have spent on cases involving HIV in corrections, jail systems and prison systems, and to a lesser but significant extent, on health care workers.

I don't disagree with the assessment I have been hearing so far, that while we stand at perilous crossroads, there are some good things to reflect on in civil rights and HIV, but if that is true as a general proposition, it is probably not very true of litigation that has had to do with corrections and with health care workers.

I'm not going to talk much about the details of corrections because I know that you all know that stuff pretty well. I think that your March 1991 report is one of the few useful and intelligent things on HIV in corrections that I have seen. I wish I had had it three years ago, but you should know it is a useful tool for people who are trying to deal with that issue.

Instead, what I thought I would do is suggest that there are a couple of things that you can draw out of the rather unhappy, mixed at best, record of HIV in corrections and health care workers that may tell us a little bit about what some of the perils up ahead at this perilous crossroads are, some of the things out of the mixed record.

I think the record is very mixed. In corrections cases where we have been looking at mass screening, discrimination in programming, proposals for segregation, we haven't had many successes at all. The only real successes I think we have seen have been in settlements, where people have been able to persuade corrections departments that they should stop doing those things because they weren't smart--

they haven't come through court decisions.

And with health care workers, where we have been looking at things like forced disclosure of people's status, and employment discrimination, while there have been a couple of good cases, most of the cases I think again when they have gone all the way have been bad.

I think there are three or four things we can learn from the record of civil rights in these cases. One of them is that we are far more ready as a society, I think, to engage in what I think of as draconian, hands-on, grab-hold-of-it, ways to react to this epidemic when we think we can do it.

It has been one of the great truisms that the most efficacious way of dealing with this epidemic is education and prevention, but behind that truism I think has always been the realization that ideas like mass screening and segregation weren't very practical anyway. When we get to areas where they have been practical--and corrections is the classic case where it has been practical--we have been all too ready as a society to turn to it and to adopt it, and for the most part, the courts have said that is fine.

We also I think as a society have been all too willing to brush aside in the most light-hearted way the serious sort of countervailing practical considerations that go along with those kinds of draconian, hands-on measures. What I have in mind--and I think I'm thinking of the same New England Journal of Medicine editorial Tom was talking about, that I suppose most of us have read that, as it works up to its suggestion for screening of health care workers and pregnant women, invokes what I think now as the "pious incantation". And the "pious incantation" with health care workers and in corrections to a lesser extent is we must of course make sure that these people's health care needs are met and that their income is replaced if they lose their jobs.

Never do we see following that a proposal of just how it is that we're going to meet these people's health care needs and who the hell is going to pay for it and how it is going to be organized. What we see is the detailed plans for the testing, which is what we really want to do.

I think in these areas that we also see a distressing willingness to adopt what I would call, for lack of a better phrase, either tired cliches or very sophistic logic, as the justification or the rationale for the measures that we want to invoke. Again, thinking for a second of health care workers, I hear the constant incantation that, well, now that we've got the ADA, now that we've made some civil rights successes, we ought to treat this just like we treat all other disease and screen health care workers--as if we did that kind of screening for every other kind of disease, as if indeed there were some sort of single reaction that we had as a society in public health to every other disease. There is no such thing. There isn't even such a thing when we're talking about sexually-transmitted diseases. We don't use the same medicine to use tuberculosis that we use to treat syphilis. We look at every illness, and we craft our response to it, one would hope, intelligently, based on what it is that we're trying to treat, what kind of risks we're looking at, what kind of spread. And the notion that we can invoke some kind of across-the-board reaction as a justification just does not make any sense at all--just as it doesn't make any sense for a court to say, well, we are going to test a person who is accused of biting a police officer--an intelligent court, made up of intelligent men and women--acknowledging that the police officer can't use the test results for his or her own behavior, acknowledging that the test results aren't going to tell the police officer anything much about his or her own sero-status, but just sort of blithely saying it will be helpful for the police officer's own health to do it so we are going to do it.

A special example of that, and one I think you have heard enough about but that I just want to add one little addition to, is what I think of as the illusion of a significant risk standard. In the civil cases that we've been talking about earlier, this notion that we should deal with HIV in terms of significant risk and ask in any situation where restrictions on behavior are proposed is there a significant risk, I think that has been something of a fraud. I don't think we have been talking about significant risk in most of those cases. I think we have been talking about imaginary risk versus real risk.

In the Chalk case, for example, we weren't really talking about whether or not there was a significant actual risk; we were talking about whether there was any risk.

What we see in most of these cases--and this comes out particularly with health care workers in corrections--is as soon as there is anything like an actual risk, then no risk is tolerable.

I was talking last week to the author of a bill in

California who wants to criminalize HIV transmission. Actually, what he wants to criminalize is if someone engages in unprotected sex or needle sharing and doesn't disclose that he or she is HIV infected that that ought to be an assault punishable by life in prison. And I said to him, "Well, maybe it's not such a bad idea, but why don't we write it generically instead of specifically?" And he said, "What do you mean?" And I said, "Well, let's write a law that says that any person who subjects another person to a very small but appreciable risk of death without disclosing that they are doing that is guilty of an assault punishable by life in prison."

And he said, "Well, yes, maybe"--and then he said, "Wait a minute. If the president of a battery company knew there was some danger from lead and did not disclose that to all of his employees, wouldn't he be guilty of an felonious assault?"

And I said, "Sure."

He said, "Well, I don't want to do that."

I said, "Why not? It's the same risk. You ought to treat like risks alike."

That, I guess, in a sense is the recommendation that I want to make to you. I think what Nan and Tom and others have said about risk and significant risk is very true, but I think maybe the situation is a little worse. I think that the significant risk standard has been a matter of rhetoric so far, and that the rhetoric is even going to start slipping back to what I am afraid is the real standard, that imaginary risks are tolerable, but nothing more is.

And I think one thing this Commission could do is to look carefully for proposals for what I suggest again are kind of draconian, hands-on measures, measures that don't contain rational assessments of risk, like mass screening for health care workers, like mass screening of pregnant women, and when those suggestions appear to take hold of your bully pulpit and to make sure that people start thinking about risk rationally, that they don't toss off the other considerations, and that the weighing is real.

The way to do that I think is by making it vivid, by making it apparent in real examples, like the example of the president of the battery company, or like the example of somebody who takes an antihistamine before they get into an automobile and then picks up other people in a car pool, subjecting them to a significant risk of death because antihistamines make you drowsy.

My point is that I think that there isn't a significant risk definition that we can intelligently use; that the meaning of significant risk is in comparison to all the other risks that we really think of as a society as significant and all the other risks that we are really willing to take, and that the way to bring this message home, to make people understand it and I think to stop some of the things we all think of are in peril, is to make those risks vivid. I think you can do that.

Thank you.

MR. DALTON: Thank you.

The next speaker is Norm Nickens. Norm actually said during the break that he thought that when he last appeared before the Commission he had been too nice, so I am a little concerned--maybe I'll limit Norm to four minutes.

[Laughter.]

STATEMENT OF MR. NORMAN H. NICKENS

MR. NICKENS: Actually, I'm going to try to keep within the time frame, which is difficult for me, because what I'm going to try to do is collapse ten years of experience down into five minutes.

Again, I am wearing a different hat from the last time I appeared before the Commission. Then I was appearing as Chair of the National Minority AIDS Council; now, I am appearing as staff of the San Francisco Human Rights Commission.

Let me just say briefly that the Human Rights Commission is the city and county agency responsible for enforcement of the city's antidiscrimination ordinances, including an ordinance that prohibits discrimination on the basis of sexual orientation--written by Matt--and an ordinance that prohibits discrimination on the basis of AIDS and HIV infection--written by Matt.

I should also add that the city recently adopted an ordinance that essentially creates domestic partnership and allowed the city to become a more compassionate, caring and equitable employer--written by Matt.

With that introduction, let me start out by saying that San Francisco is a city of roughly 700,000 people. In the last ten years of the AIDS epidemic, we have had roughly 10,300 AIDS cases, and we have had roughly 7,000 AIDS deaths. So we have lost approximately one percent of our population as a result of AIDS and HIV infection. AIDS is a very real issue for us.

Let me start by addressing in part how the Human Rights Commission got involved in this issue and then deal with the thorny question that comes up a lot, which is essentially why is the Human Rights Commission involved in civil rights issues around AIDS and HIV infection.

As I mentioned, San Francisco has been particularly hardhit by the AIDS and HIV epidemic. At the Commission, we realized very early on that we were dealing with two epidemics--the first epidemic, of the medical aspects of HIV infection, the second epidemic, of fear, hysteria, discrimination and ignorance around AIDS and the HIV epidemic.

The first identified cases of AIDS and HIV infection were diagnosed in San Francisco in the summer of 1981. At the Commission, we received our first complaint of AIDS-based discrimination in the summer of 1982. In that year, we formally investigated two complaints of AIDS-based discrimination. The following year, '83-'84, we investigated eight complaints. In '84-'85, we investigated 20 complaints. In '85-'86, we investigated 65 complaints. In that year, as a result of the rapid increase in reported instances of AIDS-based discrimination, we held two days of public hearings on discrimination against persons with AIDS, and we were able to document widespread and systemic discrimination against persons with AIDS, persons with AIDS-related conditions, and persons perceived to have AIDS or AIDS-related conditions.

On that basis, San Francisco adopted an ordinance in November of 1985 that specifically prohibits discrimination against persons with AIDS, persons with HIV infection, and persons perceived to have AIDS or HIV infection. Our ordinance covers the areas of employment, housing public accommodations, business establishments, medical services and facilities, city services and facilities, and educational institutions.

I think what is significant to note is that since our ordinance has gone into effect, our case load has essentially levelled and to some extent has actually begun to decrease. We are seeing a sharp decrease in reported instances of employment-based discrimination in San Francisco. And I want to put a very strong caveat on that, that that is in San Francisco. In surrounding counties, the case load is going through the ceiling, and we are continuing to receive phone calls from around the country.

It is not unusual in our office to receive collect phone calls from PWAs in rural areas of the country who cannot find a physician to provide care for them. It is not unusual for our office to receive collect phone calls from inmates who are in State and Federal correctional facilities all around the country who cannot find an attorney who will provide legal services to them.

What is significant here is that someone has to get pretty far down on the list of resources before they call us at San Francisco Human Rights Commission from a rural area in West Virginia to say, "I can't find a physician. Can you help me?"

As I mentioned, we saw a sharp increase in the reported instances of AIDS-based discrimination in San Francisco in a very short period. The Commission responded very early. We started accepting complaints on the basis of physical handicap. At the same time, I should note that we saw a corresponding increase in complaints of discrimination on the basis of sexual orientation. At the same time that our AIDS case load was going up, we were seeing a sharp increase in reported instances of discrimination against the lesbian and gay community in San Francisco.

My unit is simply responsible for enforcing the ordinances that Matt has authored that prohibit discriminatio on the basis of sexual orientation and AIDS and HIV infection.

I will provide you with written information, essentially our annual report, that details what our experience has been over the past ten years. That will be available as of June 20th, when it is adopted by my Commission, and I will send that out to you.

Let me briefly and very broadly describe what we have gone through--and this is very broad because the time frame is very short. In the early years of the epidemic, which I would essentially describe as 1981 through 1987, the bulk of the phone calls we were receiving at the Commission were from employees who were becoming ill, who were afraid to notify their employers of the nature of their illness for fear of losing their employment, their housing, and their access to medical care.

We saw individuals who were losing their employment because of excess absenteeism or tardiness--they were coming to work late, they were missing time for medical appointments--and they were afraid to tell their employer what was going on.

For our public hearings, we documented that that was a very real fear. In 1984 in San Francisco, if you told your employer you had AIDS, you were very likely to get fired. After our ordinance went into effect, we began seeing a change. We started getting phone calls from employers saying, "I have an employee who has AIDS. I know I can't fire him just because he has AIDS. I don't want to fire him just because he has AIDS. What do I do not?" At that point, we started working with employers and employees, providing technical assistance around reasonable accommodation.

Let me say a few things about reasonable accommodation. We now have worked with probably 2,000 PWAs in terms of providing reasonable accommodation for persons with AIDS. I contrast that number to the investigated complaints of discrimination, because in most of our cases, we are able to resolve them through education and mediation, working with an employee, to work with their employer to resolve the dispute that has come up in the workplace.

In regard to reasonable accommodation for PWAs, what we mainly see is the issue of fatigue, employees who tire very easily. So an employee may not be able to work an eight-hour shift, but he can work a six-hour shift or a four-hour shift. We have been very successful when working with employers in addressing that issue.

Where we have had problems, though, are small employers, employers who have 25 employees or less, minority-owned businesses and women-owned businesses, that very often don't have the resources to have in-house personnel departments. And we are currently mounting a campaign to work with those businesses to try to provide them with information and to provide them with accurate information about ADA. I contrast that with what is being put out by the management bar.

In about the summer of 1987 we started seeing a change. In part, it was because of the fact that we were seeing the State come on line in enforcing their protections; we were seeing the Feds come on line in enforcing their protections under the Vocational Rehabilitation Act of 1973, and that has made a real change.

We are now in essentially the third phase in San Francisco of AIDS in the workplace. The third phase is dealing with more complex reasonable accommodation arrangements, dealing with more complex insurance and benefit questions.

I'll give you one example. We are dealing with a situation now involving one of the larger employers in San Francisco. They have an excellent AIDS in the workplace education program, an excellent AIDS in the workplace benefit program, and an excellent AIDS in the workplace set of personnel policies. This policy was initially adopted in 1984, and they have one of the better track records in San Francisco. They have one particular work unit that has 50 employees in the unit, 10 of whom have AIDS. Roughly 20 percent of the work force in that particular unit is on some form of reasonable accommodation, working flexible time, flexible hours, et cetera.

What is happening now is that problems are developing between the employees who have AIDS and the employees who don't have AIDS. Some of the other employees are coming up to them and saying, "Gee, I wish I had the disease that you have so I could have all that time off." Needless to say, that is very upsetting to the PWAs, but there are also stress and burnout issues that are developing on both sides.

We are approaching this as an education problem; we are approaching this as a mediation problem. But this is the tip of the iceberg of what we will be dealing with in the Nineties.

Sliding into what I expect we'll be dealing with in the Nineties. we are seeing more women with HIV infection coming in. That is taking us more into the area of social services and access to services. We have a situation now involving a woman who requires kidney dialysis. She has only been able to find one center in Northern California that will provide kidney dialysis for her. As a result of that, she has to take three bus rides to get into San Francisco. This is a woman with HIV infection who is relatively asymptomatic at this point, but she requires kidney dialysis three times a week, and as a result of that she has to take three separate bus rides. She has to come into San Francisco to one center that will provide services.

Access to care is becoming a major issue for us. My fear in this area is that what we are seeing develop is essentially two-tiered care system. Women and people of color very often do not have access to social services and health care services.

Again, my time is short, so let me just briefly conclude by saying that our experience in San Francisco has demonstrated that strong and enforced antidiscrimination and confidentiality protections are an essential part of any city's public health response to AIDS, because without those protections, individuals will be hesitant to take the steps that they need to take to protect their health and the health of others through fear of discrimination, through fear of losing their access to health care, losing their access to employment, losing their access to insurance.

The other issue I would add to that is that in San Francisco, I think our experience has demonstrated that leadership from the top is essential. We have had strong support from day one, from the mayor's office, from the police department, from the sheriff's department. If I compare my case load to the case load of the New York City Human Rights Commission, roughly one-third of their case load involves city services. I don't get complaints against the police department. I don't get complaints against the sheriff's department--or, very rarely do I get them.

A big problem in New York is that if you call 911, if you call an ambulance, nobody is coming. I get maybe three of those cases a year. There is a difference when you have the ordinances in place, when you have the leadership from the top, and when the protections are enforced. I think we need to come back to the ADA discussion about how is this going to be enforced.

I'll stop there.

MR. DALTON: Norm, that was one of the two overriding conclusions I was drawing as you were talking--one, that you have so much to offer during the implementation phase of ADA based upon the credible experience of San Francisco; and the second overall sentiment I had, and Phillip Wiley's words were echoing in my head, was that Tulsa, Oklahoma is not San Francisco--

MR. NICKENS: That's one of the real strong caveats, that what I was saying is going on in San Francisco does not reflect what's going on in the rest of the country.

MR. DALTON: Right, but it gives us something to shoot for.

Our last speaker is Carlos Santistevan.

STATEMENT OF MR. CARLOS SANTISTEVAN

MR. SANTISTEVAN: Well, it is going to be a little difficult because almost everything that was touched probably could be touched on again. So I am going to take a different direction and talk about, rather than the obvious discrimination, the subtle discrimination that has occurred with reference to people of color, Hispanics' quality of life, understanding that due to economic and educational status, the resources for poor people are a little different, and considering that poor people deal with emergency care rather than preventive care.

Equal access in reference to information, infection control, trials availability, access to health care for the poor, incarcerated migrants, aliens--I'll cover some of that, but not all of it, because some of it has been already.

One of the concerns, coming from the street, is the publications that have come out. What has happened is you'll take an English brochure or an alien poster and translate it immediately or identically into Spanish, but not take into consideration that there is a different Spanish spoken in New York, there is a different Spanish spoken in Colorado, and there is a different Spanish spoken in Texas, yet it is all the same thing.

The second part of that is if we're going to deal with prevention and we're going to deal with the problems of infection control, then we have to have publications that deal with "el vato loco" [phonetic], "the home boy". And if you look at the posters, they don't deal with them; how can they identify, and therefore, why should they even consider looking at that?

We have to take into consideration that the Spanish spoken, again, by the ethnic groups are different. You may say something in Spanish in Colorado, and if you say that in Texas, you have insulted someone. So because of that, the publications are trying to be generic, saving money, but they are not focusing on the populations that we are dealing with.

Some of the posters and brochures, again--and remember, I am dealing with lower economic status--are written for middle class or upper middle class. Show me how to do it with a picture--don't give me a book to read, because I'm not going to read the book.

The need for trials in reference to people of color and especially economics; the need for them to go into the community. You brought out taking two or three buses. How about women who have children, babysitting? How about the problem of having to go two or three times, the transportation? Another thing that is not being considered when you go into clinical trials is if you don't have insurance. What happens after the clinical trial? That poor person is gone. The research is done, but what happens to the client? They still need the medication.

Those things have not been addressed. How do we address them?

One of the things--and this is a little off the subject--but Hispanics are constantly accused of being too "macho", and we use the term "machismo"--and even in English, they use the "macho" concept. But in HIV education, we have to get over that hump. All we talk about is condoms. We don't talk about oral sex shields, dental dams. There are people who are involved in oral sex, and dental dams are not available, so why use them?

We have to start promoting oral dental shields. We have to start using language that refers to that particular subject matter so we don't get confused and we don't continue to perpetuate the "machismo".

I give credit to the gay community; I give credit to ACT UP for the things that they have done. But we have to understand that the people of color who we are trying to access, the health and services providers, for people of color, if you are not part of the white gay community, if you are not part of--and probably the women will take offense at this--but it is the old white women's club--because they don't like to be called "girls" so we have to call them "women"--they have closed in on care providers in health services. Some of them speak Spanish, but they are not bicultural, and some of the Spanish that they are speaking is Castilian that they have learned in a book. They are not talking the "Spanglish" that is in the community; they are not talking to their clients, and in the process of talking to them with the Spanish they do know, they are talking "at" them. They are talking at them with a social worker mentality--and it is not their fault; it is just that they are not bicultural. You don't understand that you don't go down a list of things and expect to get done with an interview with an Hispanic in ten minutes, because you've got lunch. You have to understand that you have to develop a relationship with a client. You ask them how they are. You ask them how they are feeling. You ask them what is bothering them. You don't go down the checklist. That is the problem that a social worker mentality will perpetrate, and because of that, we will tell you what we want to hear; we won't tell you what you need to know.

Part of that whole concept of who you are and where you are coming from--and I mentioned being a gay white male or a gay white female--because they don't know that--and I have gone to communities that are dealing in HIV/AIDS education, and I say, "I understand you have a position open. I sure hope you get someone who is bilingual, and I sure hope you get someone from the people of color."

They say, "Oh, yes, we're looking for them. In fact, we need someone on our board, so if you know some volunteers, we have room for them."

So that those of us who are in this field are taking the lower economic positions because we feel the need to be there. And then when we are there, when you come to town, we are part of the parade. "Hi, I'm Hispanic. Yes, I work for them." But as to access, having the employees--and we have people who have the education who can do the job, who come from a bicultural background. They understand--but those people are not there.

How do we make them be there so that the quality of life for PWAs, especially those who are of color, receive the quality of care they need and receive what I hope we're trying to give them.

My five minutes are probably up.

MR. DALTON: Yes, I was actually going to cut you off about two minutes ago, and I'm glad I didn't because it gave you a chance to say something very important.

Thank you, Mr. Santistevan.

Okay. We now have about 20 minutes, because we've saved some time for public comments at 12:00, and also, commissioners need to be leaving. In fact, Eunice Diaz sent me a note explaining that she had to catch a plane and that she in fact is going to ask for the transcript of the final couple speakers because she didn't want to miss what you all had to say.

Questions, comments? Don?

MR. GOLDMAN: Mr. Coles, the example that you gave in terms of the owner of the batter factory I assume was not taken unintentionally as a hypothetical. If I recall correctly, wasn't there in fact a criminal charge brought against such a manufacturer in Illinois, or a similar kind of manufacturing setting, where an employer was in fact accused criminally of assault on his employees by knowingly engaging in a manufacturing process which caused or had the potential of causing harm to his employees; and if in fact that is an accepted understanding, do I take it then that you don't believe there is anything wrong with applying those same standards in a setting in which the risk, rather than allowing employees to be subjected to the risks of battery fumes, is acceptable?

MR. COLES: Well, I don't know if there was a prosecution like that in Illinois. I know that you couldn't prosecute somebody for felonious assault that way in California and that the penalty for felonious assault in California is two years, not life. So at least at this point I don't see society from where I see it treating those as equivalent risks.

I think probably it is a mistake to buy into the deterrence rationale anyway, that the notion that you can do serious social policy engineering, whether it be in public health particularly but almost anywhere else, by using the criminal laws, I think is a pretty stupid idea.

I really just chose the example not because I think we ought to buy into the notion of criminal law deterrence as a way of accomplishing public health but because I think it was a good example of trying to make people think about equivalent risks when they are assessing any given situation. I think the way bring significant risk home is to make people think of equivalent risks.

MR. GOLDMAN: My experience in that area is that in fact what ends up happening in most instances is that while there is a theoretical basis for the utilization of criminal laws that they end up being applied somewhat discriminatorily.

For example, in New Jersey, impossibility is not a defense to a charge of attempt under New Jersey State criminal code. Therefore, if theoretically somebody who theoretically attempts to infect somebody with HIV infection, even if it is impossible to do so, he is essentially technically theoretically liable for the charge, as much as man sitting outside a bank with a tablespoon is theoretically, if he sits there on the lawn of the bank, starting to dig a hole in the ground with the tablespoon, thinking that he is going to use that tablespoon to dig under the bank vault and somehow or other rob the bank, is theoretically liable for charges of attempted bank robbery.

The fact of the matter is, however, that that person would in fact be institutionalized and not charged. The fact of the matter is the person with HIV infection in that setting was in fact charged.

The problem that I see is not the theoretical application of the criminal laws from a legal basis but rather, the rather extraordinarily discriminatory application of those laws in that context.

On the other hand, I have also seen people not do so. In another prosecution, a Federal prosecution in New Jersey, where a physician who was charged with and in fact pled guilty to having sought money from immigration applicants to not disclose their HIV status, there was a deliberate policy decision made by the United States Attorney's Office not to suggest to the court, as could have been the case under the Federal Sentencing Guidelines, to add any increment of harm for purposes of sentencing that the public health is threatened, and recognized that even the physician's crime, however criminal it may have been to attempt to extort a poor victim of immigration status, that it wasn't one that endangered the public health, and therefore that that added increment to sentencing was inappropriate.

So that sometimes you have Government and prosecutors doing the right thing as well. I was wondering if any of you have any comments on those issues and how they might apply and what we might do about any of them.

MR. RUBENSTEIN: I think one thing that is very important to realize--and I think Matt brought this up in the context I think of making a point about a hypothetical law in

California that you were trying to beat back, and the best way of framing public dialogue around that and framing the issue.

I think one thing the Commission needs to realize is that for a lot of people, this is not just a hypothetical issue. We recently filed a brief in a case in Texas that I think is worth pausing a moment and hearing about. In this case, it involved a guy who was in prison who spit on a prison guard after an altercation. He was convicted of attempted murder; he was charged of attempted murder and convicted of it, based on the testimony of two doctors. Two doctors came down there--one of them being Dr. Lorraine Day from San Francisco, and the other one being a man named Paul Cameron, who goes around the country testifying in cases involving gay people--and those two doctors testified that there was a possibility of the prison guard getting AIDS from this and that this man should be convicted of attempted murder. He was convicted, and he was then sentenced to 99 years in prison or life, whichever lasts longer.

This is not going to be an isolated case. These cases are coming up again and again, and you have one in New Jersey with the <u>Greg Smith</u> case. This is actually happening to people, and I think it is important that the Commission come out against the so-called "doctors" who are going around and testifying in these kinds of cases, because you are a voice of public health, and you have that bully pulpit, as it has been called. And I think it is very important for prosecutors to get the message that this is bad public health and that they shouldn't use the opportunities they might have to get their names in the paper to bring cases like this, because not only do they hurt people very badly and very discriminatorily, but they send out messages about how AIDS is transmitted that end up getting far more play in the media than the message about how AIDS is and is not truly transmitted.

So I would urge you to take the opportunity to talk about that.

MR. DECKER: I think the other issue that hasn't been raised is this whole issue of testing alleged rapists and this idea that prosecutors are crying the blues that they have to negotiate and plea bargain in order to get permission for the test. I think that is an incredible statement and something that they have created in their own minds as to why they need to have that.

MR. COLES: Let me add one thing to this almost as an answer to a question earlier about how you assess the civil rights on both sides, because the prostitute testing thing reminded me of that.

I thought when there was a rape testing bill in California that in a way we missed an important opportunity. I think we should have gotten on the stick when that bill was introduced and introduced a contrary bill, taking the money that was going to be used to test the alleged perpetrators and make it available to test victims of sexual assault and provide counseling for victims of sexual assault. I think the way to sort of frame this in a civil rights context is to do that.

In almost every one of these situations we talk about--screening, segregation--there is somebody else on the other side of it, and there is something we think ought to be done for them. And we've got to make sure we don't have our own pious incantations. Of course, one must make sure that the victim has counseling--get this rape bill that we want to see beaten back, and get out there in front on making sure that sexual assault victims are taken care of.

MR. DALTON: Okay. David, then June and then Scott.

DR. ROGERS: Well, I have learned an enormous amount from all of you.

Mr. Nickens, you said something that I found important, and it seems to me it pervades this, that if you can get those in positions of political leadership to speak out courageously and unequivocally, some of these--not all--but some of the kinds of problems disappear.

I think it would be very helpful for me, perhaps for Tom Stoddard and others--you gave some data on your problems in San Francisco vis-a-vis the problems in the health department in New York City. I would personally love to have that to make use of in terms of talking with our mayor and how much of a difference it might make if he spoke out unequivocally on this. I think that kind of data would be very impressive to him.

MR. NICKENS: I can give you just a couple brief examples.

MR. DALTON: But do you have the numbers that you could in fact give--

DR. ROGERS: I saw him writing it down. Are you going to send me those?

MR. NICKENS: Yes. I'll send you basically our annual report, which for this year is going to detail our experience over the last ten years.

DR. ROGERS: I'll give you Barry Sullivan's card so you may send it to him.

MR. NICKENS: Let me step back for a moment, though, on this issue, because when our ordinance was first proposed in 1984, we went to then Mayor Feinstein and proposed that San Francisco adopt a local ordinance prohibiting discrimination on the basis of AIDS, and she was initially opposed to it.

We went back a year later and said to her let's put aside the civil rights arguments and look at how much money the city saves each time we prevent an employer from arbitrarily discriminating against someone, terminating them, and having the individual lose his ability to support himself financially, the ability to support himself medically, and having him forced onto the public sector. What our ordinance has done is help prevent the private sector from shifting an undue burden of the cost of AIDS to the public sector.

I think our ordinance is justifiable economically and in terms of public health, without even addressing the civil rights issues.

MR. DALTON: Yes, Tom.

MR. STODDARD: On the general subject of authority and leadership it is unclear to me what the Commission might consider doing in response to today's hearing and to the general subject that has been addressed today. But one of the things I think has been missing in the AIDS debate has been a document issued by an authoritative body or person that makes clear why civil liberties and civil rights questions are important in the reinforcement of public health.

That kind of document would be enormously important in dealing with the issue of civil rights and civil liberties generically. We don't have such a document now, and as a result we have to deal with all of these particular issues piecemeal and within the context of a particular debate and issue. And we lack the larger perspective that, for example, the Commission could provide generally to members of Congress and State legislators.

MS. O'NEILL: May I just follow up very briefly?

MR. DALTON: Yes, please.

MR. O'NEILL: I think the Commission could also do an enormous amount of good by working to destroy the perception that civil rights are over here, and public health issues are over here, and do it in two ways. One is looking at what is the end we want to reach, and if the end is the same thing, accomplished by the same means, whether you are saying autonomy is a good idea or whether you are saying health care decisionmaking is necessary for people to get care, then you make it clear that there is a commonality between civil rights concerns and public health concerns, that there is a common end to both of them.

The other thing I think is for the Commission to take a look at proposals and deal with the public health and medical assumptions under it that need to be looked at closely, and if I can just give one example. For instance, the pressure right now for mandatory newborn screening is based on the assumption that this is the way to identify children so that we can get children who are HIV positive into care. The assumptions that it sort of rejects are that voluntary counseling and testing of women is not as effective a way of getting children into care as coercive and mandatory in routine screening. To the extent the Commission and others can pull together data showing that people can voluntarily be tested with the result of getting children into care and without the necessity of doing mandatory testing, that is very important.

So to the extent that what you can do is to look at the medical assumptions underlying things and say that civil rights solutions for those things accomplish as effectively mandatory measures, then I think you are doing a great service to everybody.

MR. DALTON: I see Barry's and Norm's hands.

MR. SULLIVAN: One point that hasn't been made that perhaps hasn't been made because it is so obvious is what does testing tell us. The reason I bring it up is that last month I was talking to the annual meeting of the Federation of State Medical Boards, which is the association of licensing authorities for physicians in the United States, and there was an audience of about 600 or 700 people, present and past licensers, and their attorneys.

After I was through, one of the licensers from a State that I won't mention so as not to embarrass anybody came up and picked a fight with me about my position on testing. He said, "I can't understand why you insist on universal precautions when we have a test available that will tell me for certain whether somebody is HIV positive or not, and I can just decide whether to take precautions or not."

After I was scraped off the ceiling, I tried to respond to this. But it seems to me that we cannot underestimate the information that is out there, even in the medical community, about what testing will do for us and what it won't do for us.

MR. NICKENS: Let me give you just one concrete example of what you could do to help the situation and then sort of broaden some of my earlier comments about leadership.

One thing that you could do right now would be to get George Bush to stop referring to "the innocent victims of AIDS--women and children". There aren't "good" people with AIDS, there aren't "bad" people with AIDS.

[Applause.]

MR. NICKENS: Allowing that dichotomy to exist in the public mind--I can't tell you how much damage that does. That is point one.

Point two, on the issue of leadership--by that, I don't just mean leadership from the city. We clearly have had leadership in San Francisco from the highest level on down. We have also had problems. We adopted our local ordinance as a result of problems we had in the private sector, and I should add we had to go through the same process in the public sector. We have adopted civil service regulations that prohibit discrimination on the basis of AIDS and also create a disciplinary process for members of the civil service system, city and county employees, who refuse to provide services to people with AIDS.

What brought that about was a series of instances where, for example, people would come in to pay parking tickets and go into the city clerk's office and say, "I'm a person with AIDS. I am on a fixed income. I have $200 in parking tickets. Is there any way I can work it off?" And the clerk would say, "I'm sorry, I can't help you; I can't deal with a person with AIDS"--and stand up and walk out of the room.

As a result of that, we have adopted civil service procedures that deal with this. I should also add that the business community has responded and responded well. The Chamber of Commerce in San Francisco as early as 1985 came out with model guidelines on AIDS in the workplace that are excellent. Since then, we have developed a very good relationship with the Chamber--

MR. DALTON: I'm cutting you off because we are beginning to lose people to planes, we still have public comment, and I'd like to hear from our Chair and from Scott Allen and Irwin.

June?

DR. OSBORN: Actually, in addition to wanting to tell you how much I have found this a wonderful morning's worth of testimony and have learned a lot, I wanted to ask the collective advice of a group of people who know the legal system well in a variety of ways.

Harlon and I in our previous lives before the Commission had an opportunity once to be part of a group that talked to 250 judges and justices drawn together by the National Institute of Justice and some other sponsors, including the American Bar Association, for a whole day--actually, I was able to stay only for the morning--but at the lunch, I was very struck because the people I was having lunch with, the judges and justices around my table, were saying, "Now, that was really helpful. I wish I had known that when I had this or that case"--in a remarkably frank and open way, I thought. It was wonderful. And it popped instantly to mind again in the recent ruling in Princeton, which interposed itself right, smack in the middle of David's in particular efforts in Princeton to use what you are all referring to as the "bully pulpit", which I wish you would show me where that one is, because much of what you have asked us to say, most of us do spend a lot of time saying.

The point of this question, a little bit tortuous, but in order to fill it out, I wanted to quote those judges and justices, is that I think part of the reason that times are perilous now from my perception is that we are constantly being blindsided as we try to use this bully pulpit by unlettered rulings in the courts. And I don't know if you have any thoughtful advice about that; if you know of any dynamics that could be started off again to achieve something that was probably transient before, but nonetheless I think Harlon agrees--we have talked about that as having been one of the better opportunities that I at least felt that I have had.

You are all very experienced and thoughtful, and I'd love any comments or suggestions you might have.

MR. STODDARD: At the risk of being an "agent provocateur" and of seeming protective of my own profession, judges and lawyers are a problem, but I think doctors are more of a problem right now. And I wish that the same conversations that have taken place with lawyers and judges could take place within medical societies, because the public is listening to the medical societies and not to the lawyers.

MR. DALTON: But it is listening to judges when they hand down decisions and convict people of attempted murder for spitting.

MR. STODDARD: Oh, yes, no question. I don't mean to minimize it.

MR. DECKER: One practical but probably unexciting recommendation would be to contact the National Judicial College in Reno, Nevada, that does provide ongoing training of judges. I just participated in something on the elderly and the disabled, and they seemed to be open to some of these issues, and they bring over the course of time several hundred judges together--often the lower level judges, probate judges--who handle these kinds of cases. So again a request from the Commission to take up this issue might help.

MR. DALTON: Barry, and then Matt, and then Nan.

MR. SULLIVAN: When my committee proposed its policy recommendations to the American Bar Association House of Delegates, we went into the House of Delegates with the support of I think 13 or 14 different ABA entities, which did not include the Judicial Administration Division, which is the judges' section, despite the fact that we have two judges on our committee. And when I asked one of the judges about this--I was quite concerned about it--she told me that the way the dynamics worked was that those who had been to some program on AIDS supported our policy recommendations, and those who hadn't been to any program on AIDS voted against our policy recommendations.

I guess the trick is to find a forum in which you can reach judges, but you don't reach only those judges who self-select themselves into that group.

So I think that probably working with the Judicial Administration Division of the ABA to provide some kind of educational program for judges at a time when they aren't going to have an opportunity to go somewhere else is probably the best that you can do.

MR. COLES: It may be a little bit of a depressing description, but I think that there is no way you can finally say something and make sure everybody hears it and walk away and you are done with it--partly because the judges keep changing every year and partly because all the rest of us keep changing every year.

Don't underestimate the fact that having said the things you have as often as you have, that that hasn't sunk in. I meant it when I said your March 1991 report is a great tool. I wish I had had that when I was first suing the California prison system over segregation. I wish I had had somebody with some standing who would have said segregation was a bad idea. That it is there now is great. That you are going to have to say it again and again, that you will probably have to republish the report, that you will probably have to talk until you are blue in the face--yes. But it does have an effect.

I think judges ultimately really are just very average, ordinary people who reflect to a very large extent, we would hope, maybe a little bit more the intelligent side of society, but not by much, and getting to them is just like getting to all the rest of it. You just have to keep saying it.

MS. HUNTER: My other specific suggestion is going through the ABA, which I heartily endorse, is campaigning for judicial education slots at judicial conferences. I had the opportunity to talk to the Judicial Conference of the D.C. Circuit and also of the D.C. Court of Appeals and the D.C. Superior Court, judges who really deal with the family law cases, the criminal cases, the cases that come through the State court system, and I think Barry is absolutely right. If there are programs that are set up to be AIDS-specific, you will only get self-selected people there; you will not get the people to whom you most need to talk.

So I think it is really essential that they be the kind of programs that are essentially mandatory for all judges.

MR. NICKENS: Just a quick practical note. At the Federal level, I encourage you to work with the Federal Judicial Centers. They are one of the groups that does the training initially for Federal judges when they first come on, so if you can catch them before they get on the bench.

DR. OSBORN: A point of information on the issue that was raised about mandatory testing of pregnant women and so on. We try to maintain some credibility, among other things by when there is a question where there is a lot of expertise to be brought to bear that is not richly represented on the Commission, if there are other groups looking at it, we are very eager to endorse that kind of thing. There was in fact just recently the kind of authoritative study you were asking for, done by the Institute of Medicine, which I think would be quite useful in that specific context, in the same way that we are happy to know about the prison report being useful.

At the point at which that was beginning to be a very hot issue, happily the timing was such that the Institute of Medicine was ready to publish a small booklet that is usable on issues surrounding HIV testing of pregnant women that I think everybody would find useful.

MS. O'NEILL: That is very useful. I think, however, there has to be a collection of voices saying the same things, and to the extent that the Commission can put its imprimatur and its own voice in this issue, it will be very useful. And to the extent that it can find medical and health authorities to say the same thing to counteract what others are saying, that will be useful as well.

MR. DALTON: Carlos?

MR. SANTISTEVAN: I would like to encourage the Commission to consider funds for innovative projects that don't fit middle class standards; rather, an economic and people of color community standard run by that particular group, so that the communities that are now being impacted will be able to at least be prepared for this onslaught.

MR. DALTON: Thank you.

I'm going to give the chair back to June.

DR. OSBORN: And I have the pleasure of saying that the public who wanted to comment found your testimony so well-put today that there is no one who now wants to comment, which I think is a marvelous compliment that I, too, would like to convey to the people who have joined us this morning.

This really has been a very rich morning of testimony, and we are very grateful to you.

David, any comment?

DR. ROGERS: Hear, hear.

DR. OSBORN: In that case, we are adjourned, and thank you so much for your trouble.

[Whereupon, at 12:07 p.m., the proceedings were concluded.]

C-E-R-T-I-F-I-C-A-T-E

I, Anne Hayes , the Official Court Reporter for Miller Reporting Company, Inc., hereby certify that I recorded the foregoing proceedings; that the proceedings have been reduced to typewriting by me, or under my direction and that the foregoing transcript is a correct and accurate record of the proceedings to the best of my knowledge, ability and belief.

/s/ Anne Hayes