THE TRANSCRIPT OF
THE NATIONAL COMMISSION ON AIDS
WORKING GROUP ON FEDERAL, STATE AND LOCAL RESPONSIBILITIES

JANUARY 4, 1990

VOLUME I

Held at the:
Saint Paul Hotel
350 Market Street
Saint Paul, Minnesota

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(Whereupon, the following proceedings were duly had:)

MS. AHRENS: Good morning. My name is Diane Ahrens and I'll be chairing this meeting. This first meeting on the Working Group of the National Commission On AIDS is called to order. Our task over these next two days is to come to a consensus as to what the appropriate responses of federal, state, and local government ought to be in confronting the AIDS/HIV epidemic. Our consensus will be presented to the entire National Commission on AIDS for their deliberation and the commissions next meeting on January 25 in Los Angeles. To accomplish this task the commission chair, June Osborn, has appointed three members of the commission and I am pleased to introduce to you now one of my colleagues that will be with us today, Dr. Charles Konigsberg, who is the Commissioner of Health from the state of Kansas. Charles brings to this commission his broad experience in the field of public health having recently served as the District Health Program Director for Broward County, Fort Lauderdale, Florida. The second member of this working group is Larry Kessler who is the Executive Director of the AIDS Action. He lives in Boston which is a community-based organization. Larry also serves on the Massachusetts Governor's Task Force on AIDS and the Boston Mayor's Task Force On AIDS and he is a national leader in developing a community response, particularly in the volunteer sector, in addressing the

epidemic. Larry's plane has landed, I understand, at the airport and he is on his way here so he should be here very shortly. I want to welcome our distinguished presenters who we will hear from individually during this day, and of course, our guests and our visitors. I would also at this time like to introduce the commission's staff who are here from Washington and when I call their name I hope they will waive their hand or stand. Maureen Byrnes is the Executive Director of the National Commission On AIDS; Jane Silver is Senior Policy Analyst, over in the corner there; and Joan Piemme who is also a Policy Analyst, and Joan, I believe, is in the rear of the room. Pat Frank who is here with us at the head table is the Coordinator of the AIDS Resource Programs with the Institute of Health Policy Studies at the University of California in San Francisco, and Pat is going to be our facilitator for tommorrow's meeting. I know that any of the staff that are here will be available to answer any questions, either about the commission or about this meeting specifically. Laying a framework for our task I can think of no better resource than to refer briefly to the report of the commission which was issued last month to the President and to his congressional leadership on some of the testimony presented. In the commission's overview, the report stated that there is dangerous and perhaps an even growing complacency in our country toward an epidemic that many people would like to believe is over. Far from being over, the epidemic is reaching

crisis proportions among young, the poor, women, and many minority communities; in fact, the 1990's will be much worse than the 1980's. The link between drug abuse and HIV infection must be acknowledged and addressed in international drug strategy. There is no national plan for helping an already faltering health care system deal with the impact of the HIV epidemic. The public health care system in this country is not working well and nowhere is that more evident than for people with AIDS.

While AIDS is not the cause of the health care system's disarray, it may well be the crisis that will press a response for a national action to correct and share very serious short falls. In examining the scope of the problems, we need to be reminded that over the course of the next 4 years in this country AIDS will likely claim an additional 200,000 lives. By 1991, just 10 years after the first AIDS cases were reported, AIDS will far exceed all other causes of death for people between the ages of 25 and 44. In New York City alone, an estimated 100,000 intravenous drug users are HIV infected. The HIV epidemic is not just in New York City or in San Francisco as some people would like to believe. By 1991 it is expected that 80 percent of new AIDS cases will come from outside of New York City and San Francisco. In fact, as the numbers escalate there has been a disproportionate impact of HIV on disenfranchised populations: gay to poor, racial minorities, women, adolescents,

and drug users. Populations having already less than optimal access to quality health care. The development of a national care and treatment strategy will require a rethinking of our past efforts. And what about the care for those who are infected? In recent years we have seen considerable advances in the development of new HIV drugs but scientific breakthroughs mean little unless the health care system can incorporate them and make them acceptable to people in need. According to a 1987 U.S. Hospital AIDS Survey almost one quarter of all AID's patients have no form of insurance, either public or private. For the medically disenfranchised there is no access to a system of care. For those who have no doctor, no clinic, no means of payment, access to health care services, they're most often through the emergency room door of one of the few hospitals in the community that will treat AIDS patients. Those who are covered by Medicaid face obstacles as well. One obstacle is the wide variation among states in terms of Medicaid eligibility and the scope of benefits. There is no requirements that Medicaid make even life prolonging drugs such as AZT available. Another obstacle to needed care for persons with HIV to even qualify for Medicaid is a low reimbursement rate. For example. a new patient entering a office visit in New York City is compensated by Blue Cross at $78 dollars, by Medicare at $80 dollars, and by Medicaid at $7 dollars; yet there is still no national strategy for the care and treatment of HIV infected people.

Research has brought us now to the point that we urgently need to have in place such a strategy and this must be a national strategy for a number of reasons: firstly, under even the most conservative estimates, the number of infected individuals is overwhelming. The CDC currently estimates that between one million and one million one hundred thousand are presently HIV infected; secondly, the recent federal recommendation outlining prophylaxes released with no additional resources or recommendations for altering the existing piloting programs. And the health care system is already near collapse in many parts of this country. And fourthly, the disproportionate impact of HIV on disenfranchised populations and the total inability from a physical or a resource perspective for the high incident states to pay for the levels of care and treatment needed for HIV infected populations. We as a nation are totally unprepared to deal with the impact of these recent developments and until we make HIV care and treatment a national, state, and local priority, HIV will continue to kill off our population as effectively as any war, past, present or future.

And that brings us to who is responsible, who is responsible for acting? In carrying out its mandate, the National Commission On AIDS will attempt to delineate clearly the roles and responsibilities of the various levels of government and the private sector in responding to and managing

the epidemic. Today there is no national policy or plan. Without the definition of roles each level of government points its finger at another level and says, "It's their job." Clearly, managing the HIV epidemic is a responsibility which must be shared by all of us. Without federal leadership the states have assumed various degrees of responsibility for planning and coordination and the provision of care, and many local governments have played key roles in determining how patient services should be provided, and the private sector AIDS organizations have also been a very important part in managing the epidemic today.

We must, the commission was told, move swiftly to bring the missing players to the table and this includes a greater presence of our federal, state and local government in determining leadership, financing, and services. And so responding to the challenge to bring the missing players to the table, the National Commission On AIDS has appointed this working group and given us the task of translating the facts into action that we may all be held accountable for the national strategy that is long overdue.

And that, my friends, brings us to this meeting. We have set forth some goals for today's session. The first is to learn who is doing what? The second is to learn what isn't working, and the third is to learn what should be the role of the various levels of government as seen by our presenters. And to help us

in this task this morning we are pleased to welcome representatives from several national organizations that represent various levels of government. The federal government through the Department of Health and Human Services, The National Association of Counties, The U.S. Conference of Mayors, the National League of Cities, and The National Conference of State Legislatures. In the afternoon, we will here from invited guests from governmental levels as well as those in community and volunteer sectors, and our afternoon presenters will remain with us tomorrow to join with the commission members in a round-table discussion which will be facilitated by Pat Frank to drive us towards consensus on the roles of responsibility at the various levels.

And now I'm delighted to welcome to the podium Dr. James Allen who is the Director of the AIDS Program Office of the Department of Health and Human Services. And I would like to say to Jim that we feel like we are really welcoming a friend. Jim has been at all of our National AIDS Commission meetings whether or not the Secretary, Louis Sullivan, of Health and Human Services was there. He has sat with us through all of our deliberations and he provides wonderful advice and counsel, both officially and on the side to the work of the commission. So welcome to Saint Paul and to this working group, Jim.

DR. ALLEN: Thank you, good morning. I welcome the opportunity on behalf of Dr. Louis W. Sullivan,

Secretary of the Department of Health and Human Services and a member, himself, of the National Commission On AIDS, to appear before this working group of commissioners to discuss the federal role in response to the epidemic HIV infection and AIDS. I apologize that I do not have prepared copies of my testimony to distribute to you at this time. I will have copies available early next week. Since I have been asked to speak for no more than 15 minutes I will try to provide you with an overview that will serve as a framework for questions and discussion.

My discussion will start with a historical perspective, focus on the public health service response, and other programs, activities and responsibilities in the Department of Health and Human Services, and then conclude with a brief discussion of the response of other federal government departments and agencies. First the historical perspective. The first cases of the illness now known as AIDS were recognized by clinicians in early 1981 and were reported through the local health department in Los Angeles to the Center of Disease Control. Epidemiologists at CDC responded quickly forming an ad hoc task force that worked elaborately with state and local health officials and with clinicians around the country. The objectives were to define the extent of the problem through case identification reporting, to understand basic clinical and epidemiologic aspects of the problem, and to identify epidemiologic patients as rapidily as possible. And obviously at that point we didn't

know whether or not it was infectious or toxic or whatever.

Physicians and scientists at NIH also rapidly became involved treating patients referred to the clinical center, investigating epidemiologic and pathophysiologic aspects of the problem and trying to define epidemiology. Within 12 to 18 months after reporting of the first cases to CDC, the public health service had defined the basic etiology of the problem. It concentrated its search for etiology on isolation of the virus for a virus-like agent and it began to issue prevention recommendations to try to prevent further spread of the problem. By late 1982 CDC had given the New York City Department of Health monies through a cooperative agreement to establish an active surveillance system, and in 1983 additional state and local health departments were provided with monies for surveillance programs. Also in 1983 CDC worked collaboratively with the council of state and territorial epidemiologists to make AIDS a reportable condition and to establish a uniform and national surveillance system. Articles describing current information about AIDS were being published regularly in the Morbidity and Mortality Weekly Report which is CDC's weekly organ to the public health community and a toll free National AIDS Hot Line was established. Intensive efforts were also made in 1983 and the following years by the Food and Drug Administration and CDC to improve the safety of the nation's blood supply. In 1984 HIV, which of course then was being

called HVI3 or LAV, was identified as the cause of AIDS, and public health service scientists, especially those that the Food and Drug Administration and VIH, worked with private industry and academes to develop a refined analyzed test that could be marketed commercially for the protection of the blood supply, and to diagnose persons who were infected for education and prevention efforts. CDC worked elaborately with the Association of State and Territorial Public Health Laboratory directives to establish clinical laboratory training programs, to teach public health and other laboratories how to do HIV antibody testing and Western Blot confirmation, how to train others, and how to establish quality control programs to assure the validity of the test results. CDC also worked elaborately with state and local health departments to educate a candre of trainers to assure there would be people nation wide to provide counseling in prevention and education for people who wanted to be tested.

Federal monies were also awarded quickly to establish anonymous testing cites. This funding is still continuing. By 1986 federal monies were being awarded to every state as well as to a number of local health departments for prevention activities. CDC has provided public health advisors on special assignment to a number of the most heavily impacted areas to assist with program development and administration. Simultaneously with these activities NIH and the Alcohol Drug Abuse and Mental Health Administration have developed strong,

broad-based intramural and extramural research programs which have provided a wealth of new basic applied science in epidemiologic results and information.

With that background let me now provide you with a summary of the public health service areas of responsibility and the types of activities that we followed against the HIV and the AIDS epidemics. Basic science research has a clear responsibility in the public health service primarily through NIH and ADIBAUM (ph.). This includes both intramural and extramural grant programs and studies. Specific areas of focus with biomedical research include studies of HIV, the AIDS virus, and the HIV genome, immunology including immunopathogenesis and the immune response to HIV infection and development with animal models of infection and disease. Other areas of basic science research include neuroscience and neuropsychiatric aspects of HIV infection.

Behavior research, to better understand mechanisms of behavior and behavior change and the development of diagnostic methods and free agents is also important.

Two other areas that have received major emphasis during the last several years are the development of new drugs and therapies and then the clinical trials for these therapeutic agents to try to bring them rapidly to market. There is also a major effort for the development of vaccines although that has been less productive to date but does show some promise. The

drug development program includes anti-viral agents, anti-microbial agents of a wide variety to try to modify or treat the opportunistic infections that affect people with AIDS and immunomodulating and antineoplasty agents since cancer also is clearly a significant problem with people with HIV infection. NIH has made extensive efforts to develop a large, well coordinated AIDS clinic of trial groups to assure adequate numbers and variety of patients being enrolled in the clinical trials. The formal adult and pediatric AIDS clinical trial groups are now being supplemented with the recently developed community-based program for clinical research on AIDS.

The second major area of the public health service responsibility is risk assessment. Although disease surveillance and reporting programs are state and local responsibilities, the United States has the best national surveillance program because of the high degree of cooperation between the federal government and the state and local health departments. CDC has provided monies to all of the state health departments for years to facilitate AIDS case reporting and has assisted in the development of the uniform definitions and uniform reporting forms to facilitate this. In addition, we have established seroprevalance studies including the so-called Family of Surveys. This is again being carried out cooperatively through state and local health departments.

The federal role is to provide dollars, to provide

technical assistance and to assist in the development of uniform epidemiology and reporting system. We are collaborating with selected states and health departments in terms of establishing HIV reporting systems. This is really what I would term exploratory cooperation at the present time and there has not been any national decision through -- or with the State Territorial Health officers to establish a national program for HIV reporting.

Another area in risk assessment is epidemiologic studies. The federal government has played a major role although we don't have unique expertise, but we have been prominent in facilitating many of the major studies. We have done some of these directly, we have done many of them collaboratively through and with the state and local health departments, sometimes providing technical assistance and expertise, and in every instance providing dollars to facilitate these epidemiologic studies providing much of the basis of knowledge of the epidemic.

The third major area of federal government responsibility is for information, education and prevention. We have targeted these to four basic population groups, if you will. One is to the population of high risk persons regardless of what those risk factors may be. The second area is to the general population with subcategories for selected minority populations or racial and ethnic populations for whom the special messages

need to be targeted. The third group for information education programs has been schools and colleges, and a fourth group has been health care workers to assist them in evaluating accurately what their risks are and to take the appropriate methods of prevention so that they are not afraid to provide care for HIV infected people.

The mechanism for much of this information, education and prevention program has again been through the provisions of monies, through cooperative agreements or other means of giving monies to state and local health departments. In other groups, through the provision of technical assistance, and through training programs. We have given monies directly to state and local health departments to then use directly for program development or to pass on to community-based organizations. We have also been given congressional authority to provide some monies directly to community-based organizations. We've given money to the Conference of Mayors which group has worked with community-based organizations and others, and we have given money, particularly for some of our school-based educational programs, to national and regional organizations of a variety of types.

The Center for Disease Control, again with people from state and local health departments, has taken a major role in the direct development of guidelines and the publications of those guidelines. We have developed a variety of materials and

brochures and phamphlets which are available for distribution. Through our National Education Program we have developed a variety of public service announcements, advertising, we have developed a national mail-out brochure and sent that out to every household in the United States. Recall and a hot line are operated by the CDC and provide a national resource in these areas. In addition, there are hot lines that have been established for the provision of information on treatment and therapy trials.

The final area in this broad category is the enhancement of prevention capacity. We're working with an instate health department in terms of training individuals, providing laboratory courses and quality assurance programs in laboratories to facilitate the capacity enhancement at the state and local level.

The fourth major area of federal responsibility through the Public Health Service is product evaluation, research, and monitoring. This is largely carried out by the Food and Drug Administration. There are five areas that could be looked at quickly. One is for therapeutic agents and this includes the evaluation of licenser, production, monitoring and inspections for -- of companies and of the therapeutic agents that they are producing. The second area is similar types of activities in vaccine production. The third area is diagnostic free agents and test tips which includes the evaluation licenser and again

production monitoring and inspection of the production facilities. The fourth area is blood and blood products and includes the licenser and inspection of blood and plasma and collection facilities, processing facilities, and transfusion services. And the final area is that of medical devices to assure their safety and efficacy that includes setting standards and inspections of devices such as condoms, medical and surgical gloves and so on.

The fifth major area of responsibility of the Public Health Service is in the provision of -- for limited populations, clinical health services, research and delivery. We have responsibility for services through a variety of community health centers, IV drug abuse treatment centers, migrant labor health centers, selected pediatric populations and so on. We have provided a variety of grant monies for health service demonstration projects and we have limited resources for the construction and innovation of facilities including acute care and immediate care and chronic care facilities. We are expanding our research programs into these areas to assess better the access to utilization, the quality of and financing of our health care services. This is an area that is relatively new in terms of our priorities for work.

The sixth area, the Public Health Service, has responsibility for international research and assistance. We provide a variety of technical assistance to countries of the

world primarily through the World Health Organization and its regional organizations such as the Pan-American Health Organization. We have research projects developed in a number of countries through bilateral or multilateral cooperative agreements and we also collaborate closely with the World Health Organization of Local Program On AIDS for education programs, for policy development, and in similar areas of technical assistance.

Let me at this point move on to describe very briefly the responsibilities of other programs in the Department of Health and Human Services. The Health Care Financing Administration, I believe you are all fairly familiar with, has the primary responsibility for financing of selected programs through Medicaid and Medicare. The Medicaid programs in fiscal year 1989 provided a federal component for AIDS alone for approximately $490 million dollars; in fiscal year 1990 we estimate that this will increase to about $670 million dollars. The Social Security Supplemental Income Programs and Disability Income Programs have also been important. In fiscal year 1989 they have provided $199 million dollars of services, and fiscal year 1990 approximately $225 million dollars are estimated.

Under Secretary Constance Warner has been asked by Dr. Sullivan to establish a task force to review the reimbursement and financing mechanisms for medical care, this is not AIDS specifically, but much more broad based. This task force is

early in its deliberations and I don't have specific information as to how quickly we expect to have a report out. Dr. Sullivan certainly is to be concerned about this area and is taking action through the establishment of this task force to review this.

Other federal government departments and agencies also have a variety of programs and I'm not going to try to describe those in any detail except to indicate that the Veterans Administration, for example, has devoted in fiscal year 1989 approximately $142 million dollars and is estimated to have a budget of about $179 million dollars in fiscal year 1990 for AIDS related activities. It certainly will include some prevention activities although most of it goes to direct medical care. As an example of the extent of involvement of the Veterans Administration in the AIDS epidemic, approximately 6 percent of the AIDS cases reported to the Center for Disease Control have been recorded through the Veterans Administration system. The Department of Defense has a budget -- had a budget in fiscal year 1989 of about $86 million dollars and in fiscal year 1990 an estimated $107 million dollars for its HIV related programs, and it certainly would include antibody testing, prevention, education, medical care, and research in selected areas. The State Department through the Agency for International Development has a budget of about $40 million dollars, and $41 million dollars this year for technical

assistance internationally. And health departments in the federal government have a relatively small budget estimated for this fiscal year to be approximately $8 million dollars.

Let me conclude my comments at this point. It's been a very brief and quick sketch with most of the emphasis certainly on related-health. I would be pleased to answer any questions.

MS. AHRENS: I just wanted to welcome Larry Kessler to the table and say we're glad you got here safe and sound, Larry. You've already been introduced in the opening remarks.

DR. KONIGSBERG: Dr. Allen, we certainly appreciate your being with us this morning. I want to pick up on some of the points that you made. One of the recent articles that I read was by Donald Francis from the CDC wrote, I think very well, about the system of early intervention of HIV that is being used in parts of California. And what particularly struck me about that article was how the medical care was tied into the primary and secondary prevention and I was kind of wondering if you would comment on that and how you see the federal support going in -- or related to that. And I guess kind of part of what I'm driving at is, if you'd put a little historical perspective and go back to tuberculosis when that was also a dreaded disease, it was really devastating to the population in our country. Special systems of care were set up and I guess I see some parallel here. If you could kind of

comment on that and whether or not these kinds of things are being considered in leadership in the federal level?

DR. ALLEN: Very important question and we certainly agree that if we're really going to be able to attack this problem successfully in terms of secondary prevention, if you will, people who are already infected, it's very essential to have them diagnosed early, to bring them into the medical care system, and certainly obviously also to take preventive steps so they do not transmit to others.

I think you're focusing your question more on the provision of care and the prevention of their complicating, opportunistic infections through appropriate medical management. We couldn't agree more that this is very important, and certainly given the very large basic science research budget that is going into the development of therapies and clinical trials, we are emphasizing one aspect of that component because the therapies have to be there in order to provide successful secondary prevention efforts. The role that has been played, however, in directly providing monies for medical care services and paying for these is not one that has been given to the Public Health Service direct, and we certainly have had discussions with a variety of people within the department, within the administration, with congress, and we have not been given the directive within the Public Health Service to move ahead aggressively in this area, and certainly Congress is not

independently taking that responsibility by giving us either authorization or appropriations for such activities. We certainly have limited responsibility in that area, primarily through the health resources and services administration, HRSA, and we clearly have carried out our responsibilities in terms of the specific programs for clinical community health centers for pediatric demonstration projects and that sort of thing.

We have administered the money as promptly as possible and Congress has appropriated it for special reimbursements for therapies that have been proved effective. Primarily this has been for Azidothymidine, AZT. The primary agency that is responsible within the health and human services for financing has been the Health Care Financing Administration. They have certainly been aware of the issue, have responded to it as appropriate. As we all know the monies are not satisfactorily sufficient to provide full medical care for all people nor do all people qualify for the programs that have been authorized for the health care financing administration.

DR. KONIGSBERG: If I may follow up with more of a comment than a question. I think one of the things that I hope this commission will recommend, I'm not sure what form this would take, would be that somehow the federal response to AIDS, but particularly looking at the medical care aspect, will be pulled together in some kind of an overall strategy because what I think we see so often -- and I know at the state level this

leads to fragmentation at the state level, is that the financing which is the National AIDS Program Office is separate from say HRSA and this and that and the other thing is that somehow we've got to put all this into some kind of a grant strategy that will leave plenty of room for a state and local flexibility but it says, "Hey, this is an approach which is cost effective and which will work and which will tie prevention into the treatment." And I think that's probably one of the things. I don't know how some of the others feel. That leads to some frustration because I know even at the state level we have yet to, at least in my state, put together a grant strategy, and I think we kind of reflect that at the federal level.

I wanted to ask one other question, if I may. In talking to state laboratory directors, they're asking a lot of questions about what their roles will be in this rapidly changing field, particularly with respect to the use of immunologic markers, CD4 cells and this kind of thing. What's your feeling about that as an appropriate role for labs and how the federal government might support that, is that something that the state should be looking at through their public health laboratories?

DR. ALLEN: Again a very good question. I had personally hoped that we would be able to come up with markers for disease progression or status of the individual. That would be much simpler to do than to do CD4 counts which are very time consuming, tedious-type tests that require the

specimen to be fresh and to be handled very carefully, and there is incredible range of error that can creep into the test results. I hoped that we would have something developed through our research program that would be much easier to use than the CD4 cell count. It hasn't been there and at this point the CD4 cell count seems to be the best marker that we've got. It is a test that must be therefore widely available and readily used. We need to educate physicians in terms of the interpretation of it and we certainly need to work with laboratories to help them develop the capacity to do the tests accurately and reliably. And given the system of care that we have in the United States, certainly the State Health Department laboratories are going to play a major role in the training and the monitoring and the quality assurance of that. CDC has worked with the association's State and Territory Public Health Laboratory directors in development of programs. Unfortunately as always is the case, you never can anticipate and develop programs and get the budget monies for it as rapidly as is necessary. Steps are being taken in this area. This is one of the areas that I mentioned that was included, although I didn't mention it specifically when I talked about prevention and capacity enhancement. In my view, this is an extremely important area, and certainly one that we are pulling together the 1992 budget to present, and we're going to look at very carefully and I know CDC is working in this area also.

MS. AHRENS: Jim, I want to follow up on a question I think that Charles was touching on and this is a time to dream. Some of us at state and local levels see the money coming through to us in certain kinds of categorical programs which is very nice. However, does not always lead to meet the needs as we see them at the state and local level and I'm just wondering if you could sit back and dream with us for just a minute and share what you think a responsible best-integrated infection and care and support approach would be at the federal level?

DR. ALLEN: Is this on or off the record?

MS. AHRENS: Well, I don't know, does the microphone turn off?

DR. ALLEN: Ideally, we would not have categorical programs where we're focusing on a single disease to the exclusion of everything else. Ideally, we would have a medical and health care delivery system that was well integrated where at every level we had education, prevention, early diagnosis, treatment, and medical care services that were uniformly coordinated and readily available to anyone who needed it.

That's not been the way that the system in the United States has developed and I think whatever we do at this point has to work within the system and change the entire system. Not just for AIDS and HIV infection, although we all recognize that

that is the disease problem, particularly in selected cities and local areas that have been very heavily impacted, that's the disease that is bringing the system to a halt at the present time.

This, as I indicated, has not been an area that has been primarily in the past the responsibility of the Public Health Service. We are not at the present time geared up nor do we have the mandate to do that. And I think a very important role of the commission is going to be to work with the federal government, not only Health and Human Services, but the entire federal government to help define what the response ought to be. I think at the present time that much of the responsibility for AIDS has been seen to be the prevue of the Public Health Service and not widely of other groups and agencies. And I think that's been fine in terms of the response that we have provided today and that is part of why I gave the historical perspective that I did, because I think as we had the very early response from the Public Health Service, that was fine, but we failed to then broaden the response to involve all of the sectors of the federal government that we should have. And we now find that we're in the health care crises. That you can say, yes, it's been predicted, but it's been predicted really for a matter of a few years.

And I'm sure you're aware of government bureaucracies and how difficult it is to change things and to develop totally new

programs, how long it it takes to get a piece of legislation crafted and through the system so often. So I think that we do need to take a very hard look at it. We have to do that, however, from the perspective of where we're starting now and not just from what would we do if we were starting all over again because we are starting all over again. We're in the midst of this and we have to do what we can now to assure that we can meet the needs as quickly as possible.

I agree with you, there is a need for much greater coordination. My job in the Public Health Services is to try to coordinate the Public Health Service response. And believe me, with all of the major agencies that we have got, the variety of the programs, the fact that we are working with a budget of almost $1.6 billion dollars this year, I can't keep track of everything that is happening within the Public Health Service, much less in the areas of financing and overall delivery of health care services. We have to broaden the response and we have to look at how we can do this most effectively.

MR. KESSLER: Keeping with the theme of dreaming a little, and here we are in a new decade. If you had the opportunity, what would you in terms of the prevention and education, models, experiments, successes, and failures reinitiate or reform in terms of the 1990's? What do you see and think are the most sucessful and what are the things that you think have failed on a scale --. You know, obviously there

are things that have worked in some parts of the country and not in others, but we obviously need to continue the prevention and education efforts while we're working on the treatments of the vaccines. And we seem to be stuck, we're stuck in terms of national dependency now, an '80's issue, a new decade, I think no one wants to pay attention. How are we going to take those efforts or recharge them or scuddle them for the '90's?

DR. ALLEN: We don't have programs that have clearly failed nor do we have programs for which we have got clear evidence that we have had overwhelming success and that is part of our problem. We have developed a lot of programs, some of them have been developed at the federal level. More often it's federal money that's gone to the local areas, to the community-based organizations who then have developed a wide variety of programs. Unfortunately, the evaluation effort has not kept face with the development of the programs and evaluation, and as you well know, is extremely difficult to do, to really know what you are doing to be most effective.

Let me just throw out as an example, I was just before the session talking with Dr. Mike Osterhoff, who is the state epidemiologist here, and we were comparing notes and both of us agreed that much of the so-called success that we think we've seen in some of our prevention efforts may simply be the fact that the people who were at highest risk became infected or were involved very early in the epidemic. Now what seems to be a

drop-off in the rate of new infection which we superficially attributed to effective prevention programs may simply be that the populations that are left were at lower risk anyhow and they aren't becoming infected now because their behaviors don't place them at high risk. That isn't necessarily a successful prevention program. It's the fact that these people had behavior patterns and life styles throughout that never did place them at high risk. We haven't been able to sort out all these things.

My real concern as we move into the '90s in terms of where we are with this epidemic, and the prevention of it, is several fold. One is that we have adult populations that continue to be at risk and somehow we need to really educate them and effectively get the message across that prevention of infection is the most important thing that they can ever do to keep themselves healthy. That I don't care whether we get a vaccine, whether we get a real cure for this disease or effective treatment, it's never going to be as good as prevention, not becoming infected at any point in your life.

The second is that we have got to recognize that we can't ever relax on our education efforts until -- or unless we were somehow miraculously able to irridicate the virus. We have to have effective prevention efforts for our young people and this must be tied in with effective drug abuse prevention programs, it must be tied in somehow with effective sexual education

programs, and we all know how difficult this is because that then gets into areas where people make independent moral judgments.

To my mind, however, if we fail to look at this as a very broad based population -- let me strike the word poplulation, but cultural norm, that we are destined to failure. If we continue, for example, to have television programs and movies where the standard seems to be sex between people in a variety of different circumstances, nonmonogamous sexual relationships, and there is never once a mention of the potential for STD's, sexually transmitted diseases, there's potential for pregnancy, there's potential for problems of any sort. If the heros in these movies and television programs don't and can't say or use the condom word, I think that our education efforts are destined to failure. We somehow have got to set norms that are different than what are there now and it goes back to the fact that to really have effective education, you can't stop with just giving knowledge. The knowledge has got to be there and it's got to be clearly understood.

The second component has got to be effective skills. People have got to be able to use the knowledge and know how to put the knowledge into effect.

The third is the people then have to be motivated to use it personally; it is important for me to follow this behavior, to make this lifestyle choice and I'm motivated to do it and I

will therefore do it.

And then the fourth are the supporting relationships, peer relationships, peer groups, cultural norms involved that support and confirm those lifestyle choices. And given that we have a free and open society in the United States and that that is one of the great strengths of this country, we somehow have to be able to get across effectively the education messages and make this very important for every individual person if we're going to be effective.

I'm not sure that we know today how to do those programs. Part of the research program that is being carried out by the Public Health Service is looking at behavioral research, how do we get people to change their behavior and to follow that effectively. We're very early in that research program, we don't have a lot of answers yet, but it's a topic that needs to be fully discussed at all levels and that we need to give a lot of priorty to.

MS. AHRENS: Jim, I want to thank you very much. We have a lot more questions for you but you're going to be here for a while.

DR. ALLEN: Yes.

MS. AHRENS: This afternoon and with us tomorrow so we'll get to some of those. At this time I appreciate your presentation and your very open and candid answers to our questions.

At this time I want to welcome Commissioner Ann Klinger to the podium. Commissioner Klinger is the President of the National Association of Counties, she has been a leader in the National Association of Counties and certainly from her own state of California for over ten years. It's been a real pleasure for me to come to know Ann and I want to say to Ann that as a fellow county commissioner I'm just very proud of the work that you're doing with the National Association of Counties.

MS. KLINGER: Thank you, Commissioner Ahrens, and members of the National Commission on AIDS for inviting me to be here this morning to talk to you about the role of the county governments in addressing HIV infection and AIDS. You have my written testimony and in the interest of time I'm going to abbreviate my remarks as I describe the role of counties in delivering health care and the work of our task force on HIV infection and AIDS.

As the provider of last resort, counties in over 30 states are legally liable for indigent health care. County revenues set up hospital and health care in 1987 that totalled almost $15 billion dollars. Counties own and operate about 4,000 public health facilities, including hospitals and clinics, nursing homes, and health departments. As employers, counties provide health insurance to about 2 million employees nationwide. Special problems of drug abuse, AIDS, lack of

prenatal care, and the uninsured are also budgetary problems for counties. Federal dollars to state and local governments have decreased in real dollar terms by 47 percent since 1980. This revenue reality for counties has forced us to pick up many programs with local tax dollars. In just 6 years, from 1981 to 1987, counties were forced to raise their own revenues by 60 percent and a financial abyss now faces counties. Counties cannot absorp the exploding costs of indigent health care of which AIDS is a part. We have watched this epidemic grow and there is no end in sight. Counties can't bear this burden alone and we need financial assistance.

While we don't have the financial resources, counties do need to be able to take, and are willing to give, the time and attention this issue needs. We're prepared to collaborate in any way we can to the federal and state government.

As therapies prolong life and costs escalate the question before us is, who will be responsible for seeing that all persons with AIDS have access to appropriate services? This question about who pays for that care must be addressed. There is much that counties can and are doing about the AIDS epidemic.

Two years ago the National Association of Counties formed an AIDS Task Force to assure that counties were responsive to this crisis. We have copies of this publication here today for you and maybe some of you worked on that and we greatly appreciate all the time and effort that you gave to the National

Association of Counties in making that document a reality. The task force talked with experts, those who were on the front line dealing daily with AIDS patients. The report included policy goals which has become a part of NACo's permanent American County platform for health, and these goals are first, to end the AIDS epidemic through education, prevention and research toward a cure; second, to assure access to care for all persons with HIV infection, including a range of treatment services; third, to protect the human rights of all persons. This goal was considered extremely important, both for persons with AIDS and for those who do not have the disease; and fourth, to assure adequate funding for the full continuum of AIDS prevention and treatment services. And the word "adequate" was really considered to be the key. The task force recognized the need to fund necessary services while not jeopardizing other needed health care, and to really work with our severely constrained resources. In keeping with these goals, the task force urged county officials to assume the responsibility of providing community leadership, futher, to adopt HIV and AIDS policies and to make recommendations to the appropriate federal, state, and local roles in responding to the disease. The task force also developed a "peer education" program that occurs at our National Conferences. The task force told their county official colleagues, "Counties have an urgent task. AIDS is deadly. No miracle cures are in sight. AIDS knows no age, race, or sexual

barriers."

County officials must inform themselves and educate constituents about AIDS in order to stop its devastating march through all our communities. Basically, the county role is to exhibit community leadership and to develop a local plan in cooperation with diverse community groups. County officials really can be models in discouraging ignorance and in promoting the use of accurate, sensitive information. County health department professionals will be keys in educating its community and in developing a workplace policy at county offices to address the needs of workers with HIV and those who work with persons with HIV infection.

Important county roles are first to train emergency service personnel, hospital personnel and correctional facility staff on how to carry out their duties with minimum risk. Second, educational programs in all schools on preventing sexually transmitted diseases, including HIV infection, and the use of the print and electronic media. A fourth is expanding and strengthening non-hospital health care services, and if we move ahead with Diane's earlier suggestion of being able to use in the very best way so we get the best buys for our buck. I think that's very important, and we really need to continue to emphasize the risk of HIV and substance abuse.

A strong non-discrimination policy should be part of all of our county personnel guidelines. We're committed to assuring

confidentiality and voluntary testing. The information should be provided to county employees and employees should be covered for treatment of AIDS or HIV related conditions.

Counties recognize that there are important roles for federal and state officials as well. We urge the federal government to improve the testing and approval process for new drugs. Federal programs including SSI, Medicaid and Medicare need to be coordinated to meet the needs presented by AIDS. We support legislation to extend federal anti-discrimination protection in the areas of housing, employment, and insurance to people who are HIV positive. States can provide policy guidance and also leadership for all the victims. Counties need to develop policies for jails and prisons and we need to recognize concerns and find alternatives in sentencing and rehabilitating individuals who are HIV positive.

The National Commission's December 5, 1989, letter and report to President Bush was very striking. Your call to action needs to be heeded. The lack of a national plan for helping our nation's health care systems, the growing link between drug abuse and HIV infection and the dispersion of the epidemic outside of New York City and San Francisco are all cause for tremendous concern.

We recognize the overlap with chemical dependency and many counties are working on that issue and trying to see if there is treatment on demand by individuals who are addicted to

drugs. There are simply not enough clinics in the country to really accomplish that at this point. It's my understanding that a majority of New York's new AIDS cases are drug related and some areas historically have really had a disproportionate share. At one point it was estimated that 25 percent of all AIDS cases were in California. Now, unless you think that those are all in San Francisco, and Pat can certainly -- and others in San Francisco have shown us some of the best ways to deal with the problem. But lest you think they're all there, let me tell you, I come from a very rural county in the center part of the state and our population is 171,000 and we have already had 17 deaths from AIDS and we carry a case load of at least 25. We have had our first babies who have died of AIDS and the problem is really throughout the country, not only in the large metropolitan areas. One case can devastate a county budget in a rural area. When you consider that we have already had 17 deaths, picture what would happen in a county with a population of only 10,000 people but yet with an AIDS population. That is happening in California and some of those counties really do not know how they're going to cope. In many areas of the country, there are cases as large in number as San Francisco had a few years ago, so we realize that this is not going to go away. We must stop the attitude if we don't look at it and sweep it under the rug it will go away; it will not.

The commission's observation that Medicaid will not pay

for the health care needs for many persons with AIDS is right on target. Counties typically provide the care, we pick up the tab for the indigent. For those 25 percent of AIDS patients without any insurance as reported by the 1987 U.S. Hospital AIDS Survey, it is often a county government, through its own tax base that pays for the care.

In summary, the counties role in addressing the AIDS epidemic is one as a mobilizer and a planner. Counties can mobilize their communities to address the issues of education, prevention and treatment. Many have excellent plans already in place and are implementing those plans. The real problem we see is the financial one. Counties cannot continue to absorb the exploding costs of indigent health care of which AIDS is a part. I'm saying that a second time because it is a revenue reality that we all need to face. The letter and report to the President called for bringing the "Missing players to the table...including a greater presence of...local governments in terms of leadership, financing and service delivery," and certainly that we are committed to do. We realize that while we may not have the financial resources, we have a lot of skill and commitment that will be needed as we deal with this issue in our home community.

As you know, Commissioner Ahrens, through your outstanding work with NACo, we're committed to ensuring that we are at the table. We pledge our support to assist the National

Commission to frame the national strategy.

NACo recognizes the serious crisis that exists with regards to the provision and treatment of AIDS for patients suffering from AIDS. Our county public health facilities will continue to grapple with the financial as well as the human realities of this tragic disease on a constant basis. Counties will continue to face the challenge of limited resource dollars and growing needs. I appreciate this opportunity to testify and will be happy to answer any questions that you may have.

MS. AHRENS: Thank you very much, Ms. Klinger.

DR. KONIGSBERG: Commissioner Klinger, I appreciate your coming forward today. I have a couple of questions. One of the things I would like to ask you has to do with the local public health department structures throughout the country. There's been, I think, a pretty wide variation in the response there. How do you view, since you have had some experience -- a lot of experience working through NACo, to work with various counties? How would you evaluate our local public health system across the board throughout the states in terms of responding to the AIDS epidemic, and then perhaps comment on what this commission could recommend in that regard to try to improve the situation if there are some problems out there?

MS. KLINGER: I think overall our public health officials have done an outstanding job. We have

experience certainly with sexually transmitted diseases over many, many years. Our health departments are geared to treat individuals in a confidential manner, to be sure they feel they can come in for testing and for treatment, so in having an environment in which that can occur.

I think that we do need to give additional attention to AIDS. There are several topics that counties deal with that we sometimes think if we don't really acknowledge the presence that they'll go away. I mean, mental illness historically for many years has been one, syphilis and gonorrhea and other sexually transmitted diseases is something that we don't usually talk about, and it's amazing you can actually hear the word condom now on television and actually say it in meetings of this kind and in conversation and it's considered to be an okay thing to do. I mean, attitudes have changed and county health departments are changing along with that.

A lot of the change in communities about what is okay to do has come directly from the leadership of those health departments. I think we need to recognize as well that our drug abuse programs at the county level are also doing a very great deal. I think we need to give a lot of attention there because of the overlap. Some of those may be under the bureaucracy of health departments and some may be with mental health or as a separate free-standing agency, but certainly in communities such as ours. We have an individual whose county job is to go out on

the street and pass out condoms and to go be handing out bleach and doing what we do, working directly on the street with those population groups that may be hard to reach and hard to serve, and that is happening from our drug dependency program. At the same time we have major educational efforts and the other medical efforts going out under our health department, and I think that you will find that is not unusual across the country.

I'm sure there is more that can be done and there are some areas where a real effort needs to be undertaken that hasn't occurred today. I think we will see more of that going on.

MS. AHRENS: Thank you. Larry?

MR. KESSLER: Commissioner, I have an unusual question perhaps, but it's one that I'm concerned about and I'm impressed by your efforts in the association. And I believe you when you say you have effective task forces that have helped to educate other county commissioners and officials. Has there been any effort to help officials talk about AIDS in their campaigns? One of the things that occurs to me over and over is that people whether they're running for commissioner or govenor or president or mayor can talk about parks and roadways and hospitals and Medicaid but they don't get specific. And here we have a moment when the leaders, or people who are trying to be elected as leaders, can and should be talking about this particular epidemic. They certainly talk about drugs, often

talk about the legal issues involved in drugs and drug wars and so on, but rarely do we find people or candidates talking about the intersection of the epidemic of drug abuse and the epidemic of HIV or talking about things like condoms or talking about things like sex education in schools that would include AIDS education or talking about AIDS in the community as a human issue, and I'm wondering whether your association has grappled with that? And perhaps -- this is a suggestion if you haven't already done it, perhaps that might be the next layer to help candidates put AIDS on the agenda because as we heard from Dr. Allen, we're not getting it through the media often, we're not getting it through programming, but I've never seen a program ad or a PSA for a candidate say AIDS is one of my priorities and if I'm elected we're going to do the right thing. You get the gist of my question?

MS. KLINGER: I do and I agree. I have never seen a campaign brochure with someone who's holding up a condom saying. Usually it's the senior citizens or bypass or some other good public purpose activity as well. I think you make an excellent point. I think the time will come as counties have more of their own employees die from AIDS, I think you will find attitudes changing and more attention given to the subject. I have not seen it discussed as a primary platform in anyones individual campaign with possibly the exception of some candidates in San Francisco City and County but not so much in

other parts of the country, but I think you make a very good point and that certainly is something as we're educating ourselves and our peer educational program, that certainly is something that we can bring up and it's an excellent suggestion and can suggest that that is another issue that needs to be addressed along with all of the other problems that were being solved. Whether it's a bridge falling down that could harm the safety and the economic welfare of the community, certainly AIDS is an economic issue and a tremendous loss to business as a result of this crisis.

MS. AHRENS: Ann, I have a final question here, I guess it goes to what makes community response. A lot of us think that if it ain't local it ain't real, or that people live their lives in neighborhoods and they die in neighborhoods. And if service and care is not given at the local level, it isn't going to be given, and as you travel around the country and visit counties and perhaps observe what their responses are, maybe you could just share with us what you consider to be the dynamic or the thing that makes for good response at the local level and how communities that are responding well have come to do that?

MS. KLINGER: I think communities that have really faced the issue head on tend to have an openness about what their county government does, is involved in, and tends to have a great deal of citizen participation in their communities.

I think those are key components of any program that we have. If the public is not accepting of a subject matter or a particular program, it's not going to go as far as if there is good community acceptance and recognition. Number one, that a problem exists and number two, that something has to be done about it. I really think that educating the public as a whole, breaking it in, working on this issue as we deal with our editorial boards in our home communities, being willing to talk about the problems honestly and openly, I think that those are some of the things that we can do. That's really a matter of community leadership. We do it when it comes to school dropouts, we do it when it comes to teenage pregnancies. Some of those issues also not only are overlapping the AIDS issue as we see now with so many babies being born with AIDS, but as we talk about those topics it's a natural to also discuss the impact of AIDS that overlays a lot of those problems. I think that is really what we can do and this is what leadership is all about.

MS. AHRENS: Thank you so much. So glad you're here.

MS. KLINGER: Thank you.

MS. AHRENS: I know that we're running a bit late. Brian Coyle is here from the National League of Cities but before Brian comes forward there is coffee on the table. I think we'll just stand for five minutes. I'm going to keep it

to five minutes, and then we'll move ahead with out next presenter.

(WHEREUPON, a short recess was taken.)

MS. AHRENS: I would like to welcome at this time Council Member Brian Coyle, who I understand is the vice-chair newly elected to that. He's here on behalf of the Minneapolis City Council and is here speaking on behalf of the National League of Cities. Welcome to Saint Paul, Brian.

MR. COYLE: Thank you. Thank you for the invitation. First, I would like to introduce myself. My name is Brian Coyle and I represent roughly 28,000 inner-city residents of the Sixth Ward in Minneapolis. My election in the fall of 1983 as the first openly gay member of the Minneapolis City Council; and recent inauguration, January 2nd, as Vice President of our Council after winning 80 percent of the vote for a third term represents the steady political progress that gay people have made in this marvelous country during the last decade.

But ironically, during the same time that our long uphill struggle for America's grudging acceptance and even respectability has advanced, the AIDS epidemic has haunted this progress killing off our friends and yet challenging us to create a community of caring people rather than a subculture of strangers.

As local officials and citizens, we end the decade of the

1980's faced with major problems like AIDS, crack, homelessness, that we couldn't have anticipated at its beginning.

To its credit, the City of Minneapolis has responded to the AIDS epidemic by first listening to community-initiated proposals and then by putting early money into anticipatory projects which Hennepin County, the Minnesota Department of Health, private foundations, and the community has later funded with substantially larger contributions.

Although it may sound like bragging, I am proud of the role that myself, the City Council, and our Public Health Department have played since 1984 in funding first the prevention education programs of the Minnesota AIDS Project, then the mass media campaign of the Metro Consortium, a transitional housing program which the Minneapolis/Saint Paul Family Housing Fund whose board I sit on also underwrote, and a clean-needle project which reaches out to addicts, and most recently specialized education for women, people of color, and youth.

As well as funding community-based efforts, the Minneapolis Public Health Department maintains its own modest but effective AIDS Risk Reduction Programs funded by both General Fund tax dollars and State Health grants. However, despite these extensive efforts in Minneapolis and around the nation, AIDS is becoming America's top public health problem, with its burden especially heavy on the cities. Even back in

1985 when our first lobbying effort uniting gay and straight local officials visited Capitol Hill during the National League of Cities Conference, and we've been there every year since, the city of San Francisco, for instance, was already spending more than $7 million dollars a year as the main provider of treatment, education and prevention services. At historic meetings with Reagan health officials, House Speaker O'Neil, congressional committee chairs, and our own state delegations; we pointed out that America's cities cannot be expected to fight this crisis alone. Although annual lobbying efforts since then have helped to raise federal funding from $200 million dollars to more than $1 billion dollars a year now, local government and community-based volunteer programs are still experiencing a critical need and receiving insufficient resources from Washington. Despite persistent lobbying efforts, marches on Washington, tours of the AIDS Quilt, and more than 60,000 deaths, higher than the total American fatalities in the Vietnam War, the federal government has failed to even trickle-down funds to the community level. A not-so-benign neglect has been official Washington's response.

And now, at a critical juncture for many cities dealing with the AIDS epidemic, when we will see if the overstressed health care systems of New York, Los Angeles, San Francisco, and others can cope with the manyfold increase in HIV cases, the latest word from Washington is that AIDS is overfunded and that

other diseases should take priority.

AIDS is not by any means the only health care problem in our nation and its cities. Here in the Twin Cities even I would argue that bringing down high infant mortality rates, for instance, should also have high priority; but a system overwhelmed by AIDS will be even less able to deal with other outstanding health problems. And the lessons that the HIV epidemic teaches us can be used to solve other research and health care questions. In fact, if the AIDS epidemic teaches us anything; it is that the whole health care system needs a major overhaul. Even a group of top executives acknowledged recently that failure to act will render the health care system unable to care for everyone who gets sick. Felix G. Rohatyn, the New York financier who played such an important role as chairman of the Municipal Assistance Corporation in New York has called AIDS, "A far more serious challenge than the city's fiscal crisis in the 1970s." I agree with those executives who told Governor Cuomo that cities like New York need more hospital, nursing home and home care services even if it takes additional taxes to pay for them.

Nationally I think that it is time for local, county, and state officials to descend upon Washington this year, later to be followed in 1991 by mass peoples' lobbies to demand that federal funding for prevention education efforts be renewed, that support for community-based health care be increased, and

that the way the FDA tests and distributes drugs should be changed.

Money is not only our major problem. What is needed is the reorganization of services and new systems to finance them. Minnesota has much to teach the nation about the role of decentralized medical centers, health maintenance organizations, community-based case management, coordinated interagency public health strategies, and aggressive educational and media campaigns. My appendices include four solid pages of local organizations providing HIV-related programs here in the Twin Cities summarized by the Hennepin County AIDS Task Force. The Twin Cities and Greater Minnesota have not been slow to respond to the HIV epidemic nor has there been the failure at all levels of government and the medical establishment that has characterized New York and several other major coastal cities. But we cannot afford to become complacent whether on the planetary level where the World Health Organization says indifference and denial threatens to cripple efforts to counter an expected tenfold increase in AIDS cases during the 1990s or here in Minnesota where the impact of the AIDS epidemic was delayed and the rate of new cases aren't rising as fast as it was three years ago. The lead time that enabled Minnesota to respond in a rationale manner and the current encouraging trends may be only temporary according to the Minnesota Department of Health officials. The 500-plus cases currently documented

indicate just the tip of the iceberg, and the state epidemiologist is not ready to change his projections that the total will reach 1,500 to 1,900 by the end of this new year, more than triple the number of the entire 1980's.

When you put very recognizable faces of constituents, acquaintances, close friends behind these grim statistics you can only conclude that we are still moving too slow and have not done enough to catch up with the furture shock impact of this deadly epidemic. In closing, I would like to invoke both a personal note of sorrow and a global observation. These two beautiful men, Bert Henningson and Dick Hanson, Minnesota farmers, citizen activists, and good friends of mine taught me that in facing death we can achieve the inner peace and grace that will allow us to know it is but a doorway into another life. People with AIDS are daily teaching me that living fully in each present moment, loving ourselves and the universe in which we live, is the real lesson of the AIDS crisis.

Despite our progress and failures in moving our social system to respond to the HIV epidemic, the untold development has been the struggle of people with AIDS to make attitudinal shifts and devise healing programs around self-worth that are as powerful, if not more so, than any drug or medical therapy currently out on the market. Aspiring survivors across the country are changing their behavior and taking charge of their lives through programs of nutrition, exercise, and spiritual

focus to accelerate the healing process. They deserve our support and encouragement.

AIDS was unknown when the 1980's began. Since then this deadly disease has changed how Americans think, feel, and act. These attitudinal shifts are as important as more funding, education, research discoveries, and health care delivery systems. Quite frankly, I believe that Dr. C. Everett Koop and Louise Hay have done more to teach compassion for and self-respect by people with AIDS than any politician or medical professional has. President Reagan kept his head in the sand even as his friend Rock Hudson was dying; and Bush hasn't done much better at rebuffing condemnation of the majority of AIDS patients, preferring instead to symbolically visit children in the hospital rather than homosexuals, women, people of color, youth or drug addicts.

I urge you as a Commission to insist that the President and congress break the silence of denial and speak out candidly about the ways to curb the spread of the HIV virus and why those who are infected deserve our love and compassion. A new world is taking shape around us. Barriers are coming down around the world. The fences of the world's political geography are falling fast as we become one global economy just as the HIV virus spreads rapidly worldwide. Here at home we have a chance to reinvest the so-called peace dividend and to tear down our own social walls. We need to speak out against those who would

abridge our rights, neglect our health and safety, or spread fear and hatred. But we also need to be even more mindful of our own self-hating thoughts. Our own homophobia, racism, sexism, ageism, class prejudices, and basis of addiction can be even more poisonous and harmful than the hate we receive from those who pander to fear. We need to respect ourselves and one another and to be mindful that we are part of the whole community and planet, all of us. No person or group of people is dispensable or to be excluded. Nobody is "them". We are all interrelated, an extended family. As our local media campaign slogan in the fight against AIDS says: "We are all one."

Despite awesome and unpredictable plagues like AIDS, this last 25 years of the 20th Century is indeed an exciting time in which to live. We approach not only the close of the century but the close of a millennium. God's gift of free will allows us to choose the future we will experience. We can decry our ability to affect policy on a grand scale, or recognize that change begins within ourselves and within our own communities.

Let us follow the lead of the people of East Europe, the students of China, the compassionate volunteers who help America's people with AIDS and reach out to touch those with whose lives we come in contact. In doing so, we may initiate a chain of events larger than anything we could ever imagine.

Thank you for your attention and may God Bless your efforts to understand and lead the fight against AIDS. If you

have any questions, I will be happy to answer them.

MS. AHRENS: Thank you so much, Brian. I think perhaps we sense now why you were elected by such an overwhelming margin.

MR. KESSLER: I guess the question that I have, Brian, is what you're finding as far as at the local level? Hennepin County and the City of Minneapolis and the Minneapolis AIDS Project and other groups here have had such an exemplary record in terms of building a partnership. Do you see that -- where do you see that now in 1990?

MR. COYLE: I think that's a question that everybody is asking around the country, including here. As I said, we have the -- the rate of development came slower here which allowed us to have, frankly, lead time to organize, plus Minnesota just has wonderful tradition in responding compassionately to things.

I would say that while we may be better organized and more sustained right now than many other cities who are experiencing burn out in just unbelievable case loads, we're approaching that. Perhaps not ironically in dollars and so on because we seem to still have fairly good funding of things. It's never enough and so even though I brag about the City of Minneapolis, I don't think it spends enough on the AIDS issue, but then again I don't think it spends enough on child health care as well.

I would say that I'm more worried, at least in this particular city and area, about where our minds are at, where our attitudes are at, and when I hear about other cities where there is very good reason for burn out, that troubles me even more. I think we would be greatly helped not only by seeing money trickle-down and really arrive finally at the community level, and it certainly would help local and county governments, but I think it would also really help with more direction, more outspokenness from a national level of government. And I love the fact that you asked the County Commissioner if people could campaign around the AIDS issue. I would like to see the President, as I said in my remarks, actually speak out more forcefully, and for that matter I would like to see my own colleagues do the same. I have spoken on AIDS as one of my many issues when I've campaigned, and my opponent has, although admittedly it's pretty much directed towards the gay community, and even with an openly gay politician it is very difficult to go out to a large audience and talk about AIDS directly to the people. Where we have occasion to do that though, we do, but I think we need as much political will in speaking out as we do for more money and more reorganization and medical services.

DR. KONIGSBERG: What do you see are the most critical areas that we really need to deal with as we go into 1990 with respect to AIDS and HIV? What really strikes you as the real tough things we need to work on immediately?

MR. COYLE: Frankly, I think that -- and I have lobbied now for five years every March with the National League of Cities folks, and I think you will hear from Ms. Palmer from Dallas this afternoon who has been an excellent friend to lobby with, but I think that we need to see money come more to the community level. And by that I mean nonprofits and others that are fighting the disease and certainly services, Medicare, Medicaid, Food Stamps, everything for people with AIDS. What still strikes me about this disease plus other diseases in my Ward is that there is a separation between those that have and those that don't. And quite frankly, if you're gay and bisexual and you're living in the Sixth Ward and you're employed, you at least belong here employed, have probably an HMO Health Care Program in the state of Minnesota. That then enables you if you are tested at the Red Door Clinic to a follow-up and to nurture and assist yourself. You also have access to the wonderful programs of MAP, Aliveness Project and everything else. What concerns me even though it is developing slower, thank God, in this state than in New Jersey or New York or San Francisco is the people of color, people with little money, drug addicts at Franklin and Chicago where our clean-needle program reaches out in my Ward, they don't have access to the system although Hennepin County Medical is excellent, they're not going to be as quick to act on things. If you're frankly addicted and you're living off the street and

you're drinking Lysol and you're a native American, then you may not know you have AIDS for months because you may not know during the day just how your health is doing in general. And I'm concerned as I see the spread of needles -- I have literally pick up needles on my own boulevard, behind my garage that are clearly being used by young people in my Ward. It's taken about two years to get a program that's starting to reach out to people. I worry that we're still going to see growth, even though in Minnesota we don't think so, in a larger population beyond gay and bisexuals and that it's going to be, frankly, increasingly the disease as it is nationally of the poor. And I just -- if anything in the '90's, I worry the most about is nonresponse to -- and anything possible to make things successful and easy to plug into and to use should be done for the people with AIDS.

DR. KONIGSBERG: Thank you. Do you think we need special systems of care for persons with the HIV infection and AIDS, something to -- well, certainly integrated with the mental private health care system and also somewhat separated, do you think that's needed?

MR. COYLE: Yes, I do, and I think we have the beginnings of that here although sometimes it too can be awkward. And the irony is we chose as a strategy to have decentralized medical facilities, for instance, rather than one main support. So you have at least six hospitals in Minneapolis

and Saint Paul that are fairly seasoned in dealing with people with AIDS. On the other hand, the irony is that doesn't necessarily mean that a person on the street who is poor knows where to go other than maybe Hennepin County, because the irony is they don't know where -- the one place to go neccessarily.

Similarily we have had, I think, fairly good case management programs from the beginning that were community-based but the volunteers in those and the Minnesota AIDS Project are still gaining volunteers, compared to San Francisco or L.A. where people have now been dealing with this for five years and are burning out, but even with that I think it's sometimes a cumbersome and somewhat even bureaucratic approach to things so you get more criticism.

MS. AHRENS: Brian, maybe you could share with us, if you had your dreams, what would you be asking for or wanting from the federal level and what would you be asking for or wanting from the state level?

MR. COYLE: Well, to me, the most exciting moment in lobbying was not meeting Tip O'Neil in his office or the chairs of the key committees which we've seen every year now like Mr. Thatcher and so forth and Paul Saad, but quite frankly it was going to meet the lady at 4:30 on Friday who was one of the archivists of the budget office because that's the person who actually sits there and says, "How much do you need and for what?" I think that Congress, the idea of research and so on

and money for the CDC and Public Health Institute and so on which are the first questions you get, who should it go to and so forth, are more attractive and are frankly payroll questions, rather than how do you get it down to the local level. And so for me that day at 4:30 on Friday meeting with the budget official who had the powerto distribute and to make some recommendations that would follow upon all the nice testimony before congressional committees, was kind of like meeting with our own finance department about how much money we could spend on this issue this year. It wasn't a lot of money to question where it's going to go, and I frankly think that state and local county officials should spend some more time trying to meet with those people during this year to better make sure that the programs are actually reaching down because the Minnesota AIDS Project, for instance, I think is -- as I remember a recent report of this, it's doing very well this year, and kind of surprisingly so, it's already garnered about two-thirds of its funding for this year and doing better than it has in the last two years. But what worries me is next year and the year after that because I frankly think in this area the AIDS vote is passing now as through those national headlines in the New York Times of last week alarmed me when I see, "Diseases being pitted against one another." I would love, frankly, to be marching on Washington with every part of the health care movement, not just on AIDS but many other issues, frankly. And to me I can't help

but see comparisons between this issue and for instance drug people in my Ward. I think that the drug movement which is somewhat ossified, you know, drug abuse programs tend to not reach out enough and the irony is the AIDS efforts of the 1980's in teaching is kind of revitalizing some of the drug efforts, especially minorities in my area, to reach back out, to actually be there for people in tables at community festivals and gatherings that for years we were absent from, and we need much more of that. I personally would like to see support groups that are even neighborhood based for people with AIDS as I would they are most block-based for the people who are indigent, at least for parts of my Ward. You almost need the equivalent of an AA group with a broken lock if you have 2-or-300 addicts in a 4-block radius which I do in 3 or 4 parts of my Ward. You need that kind of decentralized effort and there does need to be paid coordination and expertise brought to those groups, even if they're community-based efforts, and we still don't see enough of that money coming down.

The one good thing I think the City of Minneapolis has done, it's never spent that money on this issue; however, it's been there with early money and very few strings attached. We helped with the very first AIDS money for prevention when frankly every other level of government didn't know if they wanted to be talking about housing. We were there with the first money for the transitional housing program. We agree

there was big bucks behind it, but if we hadn't been there I'm not sure that housing would have been considered that important. Similarily we were there with the clean-needle program and congress is still discussing whether they should support it. If anything, that's what we have done, is kind of been ground breakers.

MS. AHRENS: Good for you, Jim. Thank you very much and thank you for that very compelling testimony.

MR. COYLE: Thank you.

MS. AHRENS: At this time we want to welcome Mayor Don Fraser from the City of Minneapolis. Don is an old friend to many of us. When we have such competent and compassionate political leadership, sometimes we take them for granted, and Don, your sort of like an old shoe and we have sort of taken you for granted but we shouldn't do that and we welcome you very, very sincerely to this hearing and especially to the City of Saint Paul.

MAYOR FRASER: Thank you very much Madam Chair. I always like to come to Saint Paul and to get my visa renewed. In comparison to an old shoe, I think it's disasterous and I have worn a few holes in the bottom. I just wanted to comment on my colleagues testimony immediately before me, Brian Coyle. Not only can you see now why he was elected but why he was also elected vice president to the City Council. He has taken the lead on the AIDS issue for the City of Minneapolis and

we have been fortunate to have his interest and knowledge to help lead us. With me on my right is Richard Johnson who is Staff of the United States Conference of Mayors. I'm Chairman of the Health Committee of the United States Conference of Mayors, and in the prepared statement that you have I have identified some of the current status figures for our community, and if you have questions about that David Lurie who is our Commissioner of Health is here and he's here in two capacities. He's not only our Health Commissioner of Minneapolis, but he's also President of the National Conference of the Local Health Commission in which that conference works with the United States Conference of Mayors so we've got a friendly, nice arrangement going here in terms of my role and his role at the national level. I want to thank the Commission for these hearings. I'll try to stay within my time limit here if I can. As you know the first notice of this disease in its greatest concentration was in our major cities. This trend does continues to this day, although its centralization is lessening. As predicted, HIV has spread beyond the major cities to virtually every area of the country. The roles that have been developed by mayors and by cities have been as diverse as the cities themselves so I am here today representing mayors and their cities, and I have been requested to address our role in the epidemic.

There is no one representative or single standard role for our cities and that's because of their diversity, their

history, their involvement with public health, with education, with drug treatment, and the provision of social services. Clearly, you simply can't compare New York with Cedar Rapids, Iowa. From the earliest days of the epidemic to the present, cities have had one thing in common and that is the need for involvement. As this disease has struck each of our cities, the lack of response in other quarters has placed a heavy burden on local government. Because we are affected before state governments and because the impact of AIDS on us is more personal than that of the federal government level, and I think Brian's reference to two of our good friends makes clear how that works and how the impact is felt, and because the people who have been dying live in the cities. Let me turn to the local role of responding to AIDS.

The United States Conference of Mayors views the local role as first, assessing the growing incidence of HIV infection and affected populations and the related need for treatment and support services; second, providing leadership in program planning and development and the establishment of appropriate policies; third, is assuring or providing services within resource capabilities of cities, providing education and prevention services and advocating for state and federal resources to address the disproportionate need in the cities. As well as advocating for support and funding of medical research which is essential in combating this epidemic and which

must be sufficiently funded at the federal level in the national interest.

Let me now identify now 11 major areas in which we at the city level must be involved. First, taking part in all HIV-related planning; secondly, providing community education and prevention services; third, supporting equal access to testing and counseling sites; fourth, supporting the need to maintain confidentiality of those tested; the next, collaborating with agencies and providers to deliver programs that meet identified need; supporting access to comprehensive services for people at all points on the spectrum of HIV disease; supporting the need for programs to those at highest risk and provided by organizations -- I think Brian Coyle made this point quite forcefully -- organizations serving those groups; assure that local employment practices do not discriminate against those with HIV-related disease; training city employees about AIDS and how to prevent its transmission; promoting and supporting AIDS education in our elementary and our secondary schools; and finally, encouraging local business interests to develop sound employment practices and employee education programs. While we advocate for state and federal resources to effectively address this major public health epidemic, we have been forced to act now at the local level in each of these major roles in order to preserve and protect the human resources which are concentrated in our cities.

I would like to turn now to three primary roles at the local government level: planning and coordination; education; and health care and supportive services. The traditional planning role of localities in responding to HIV has primarily included, first, assessing the incidence of HIV infection and affected populations and the related need for prevention, treatment, and support services; and second, providing leadership in program planning and development and the establishment of appropriate policies. Since 1984, the Conference of Mayors has tracked the activities of communities throughout the nation in planning and coordinating local responses to AIDS and in developing AIDS policies. There is significant expertise in our cities in planning and policymaking for AIDS. Unfortunately, the worst of AIDS is yet to come. The commission has already noted a growing complacency in the nation with regard to HIV infection. We cannot allow this to happen. Planning and coordination is clearly critical in establishing cost-effective and compassionate health care services that emphasize outpatient and continuum of care components. So we need to prepare and proceed with the recognition that planning and coordinating for HIV is best carried out with a focus upon the needs of localities and that localities represent a wealth of expertise, of education and service providers, policymakers, and innovative thinkers.

As is the case with Minnesota's planning for persons with

HIV infection, it is anticiapted that state and federal resources will be required to meet the need. Planning is critical given that many of the local HIV care and education systems, a number of which were created just within the past 6-8 years, cannot withstand the long-term stresses of the HIV epidemic, pressures of financing, increasing caseloads, and range of services needed. This is true for America's largest cities as well as for the growing number of urban areas that will experience increasing numbers of cases in coming years.

Local: Now, on education's side, we are on the front lines of the local government in providing AIDS education, typically in partnership with community-based organizations. Local education activities included HIV counseling and testing, which is an important educational intervention, most often carred out by local health departments. Education and training for our police and our fire personnel, emergency medical personnel, funding of community-based education, training of community-based personnel in providing HIV health education; and often through local government personnel who are active participants in the formation of community-based organizations that have been created to serve as major providers of the community HIV education. So the education success has been evidenced in a number of communities, including the community-based programs funded by the United States Conference of Mayors. We have provided $3.32 million to 116 projects since

1985, through the CDC, Center for Disease Control funds. Other major resources include: state health department funds primarily provided by the CDC, for community-based efforts in the states; and foundation-supported education efforts. Within the past few months, CDC has undertaken a role in conducting direct funding of community-based education. Clearly, the focus on education cannot be diminished. There can't be seen to exist in trade-off between education and the advantages of early intervention, both are critical, but the future, in particular, need for long-term education reinforces messages of safer sex with increased emphasis on supportive education for persons with HIV infection, such as the recently initiated pilot education project of the United States Conference of Mayors, funded by the CDC, which provides funds to communities to enhance education and service coordination for persons with the HIV infection.

Now, the third area, health care and supportive services. We have taken on at the local level a variety of efforts in coordinating health care and supportive services for people with AIDS and HIV infection depending a lot on how the cities have typically organized their public health responsibilities. Some cities have under their jurisdiction public hospitals which historically have been committed to paying -- or I should say serving individuals regardless of their ability to pay. Some cities handle public hospitals and these major urban public hospitals are notable for the great volume of care they provide,

and by their major role in the education of physicians and other health care workers. Establishing comprehensive continuum of care programs, which in the long run will surely save money and save lives, have not taken shape in many financially strapped areas due to the current crisis in public hospitals.

Staying on the present course or making small, incremental changes in the health care system will not do the job. System-wide changes are in order. In short-term, the federal government in league with state and local governments must encourage or mandate the distribution of the burden of care more equitably among all providers, public and private. Private payers should be held accountable by states and localities for covering AIDS treatment costs without penalizing their beneficiaries.

States, in cooperation with the federal government, should guarantee a minimum level of Medicaid rebursement to ensure more equitable coverage of inpatient care and relieve the disproportionate burden on public hospitals. Additionally, outpatient Medicaid reimbursement, which continues to be inadequate, should be strengthened to compensate for outpatient and clinic services that may be more appropriate for people with AIDS and HIV infection.

Madam Chair, those are the three main points. I know I've ran my 10 minutes but I just want to touch on a couple more as well and I'll be through.

Substance abuse services: It seems clear that the AIDS problem is now more increasingly concentrated in the poverty-stricken areas of our cities. And increasingly, it seems to be associated with drug abuse and we need to recognize that in the ways in which we are using the resources that need to be made available. I have listed in my statement some of those efforts that must be increased.

The second area I want to touch on is the problem of discrimination. Now, a number of localities have passed ordinances that have banned discrimination against people with AIDS and HIV infection in additional areas of employment and housing and public accommodations. In 1988, the United States Conference of Mayors called for federal legislation to protect the rights of persons with AIDS and HIV infection. That year, the President's commission on the HIV epidemic issued its recommendations which called for the same comprehensive government response to ban discrimination; but in the year and a half since there's been no augmentation of that recommendation. There was some progress with the Americans with Disabilities Act and that will extend protections to persons with AIDS and HIV in private as well as public settings. The problem is that a person with AIDS who is having trouble getting housing usually has to wait to go through the regular Civil Rights -- going to the nearest federal office of Civil Rights to find out if he or she has a place to sleep that night. So we need to look for

more expeditious remedies.

Early intervention: We need to initiate comprehensive early intervention for persons with HIV infection. Again, I've spelled it out at some length.

Finally, financing: The cities that have had to take on this burden and the burden has fallen very unevenly and my hope is that with the allegation of more federal resources there can be more equity in where the burden falls, in precedent, the consequences of this infectious disease. The United States Conference of Mayors have been early involved in this issue, we have been actively participating in helping to fund local programs.

I just want to conclude with reference to a statement that Mayor Art Agnos of San Francisco made about a year ago, a remarkably useful statement. He made the point -- this was actually just last June, that there are nearly 100 cities that have the same or more AIDS cases than San Francisco did in its first year of the epidemic. Given an incubation period of anywhere from 10 to 14 years, the history of San Francisco is the future of the other cities. So this is a problem that demands an adequate response, more adequate response than I think we have found up to now. Thank you very much.

MS. AHRENS: Thank you very much. Charles?

DR. KONIGSBERG: Mayor Fraser, I think you outlined very, very well what it's like to try and deal with

response to the AIDS issue at the local level. As you were the local Health Director for a number of years before you moved to the state level, I think you really summarized it extremely well and I would just kind of like to re-emphasize the planning and the coordination of the organizer's response to the leadership function which I think you demonstrated very, very well. I guess my question would be, and I think you eluded to it in your statement, when we're looking at the three levels of government, federal, state and local, how they should respond to the HIV epidemic and what the government roles are, what do you think that the federal and state governments could do better than it's doing now to support the county and local roles that you outlined? And again, I know money is part of it, but the particular areas that you think that the state and federal needs to help with?

MAYOR FRASER: Well, when you say you know the money is part of it you want to go on to the next point, I guess.

DR. KONIGSBERG: Well, even with the money, where do you think that money ought to be targeted and in what ways?

MAYOR FRASER: Well, clearly, one of the needs is to be without -- based on unfair and unevenness and burden in government and part of that would come through making sure that reimbursement is adequate and that all coverages are

adequate. One of the things that I'm -- perhaps this is more of my own opinion than official policy, but this morning I was speaking to a group of business people about early childhood interventions and the problem of poverty and the dysfunctional nature of too many families in nurturing and providing for children. In a larger context, I see this where the AIDS problem is now tending to be concentrated as pieces of a larger kind of social disintegration is going on in our cities. If drug abusers using needles are our primary means now of transmission of the HIV infection, one of the questions then would be, how do we decrease the number of people who become addicted to the use of drugs? The only effective strategy that I've heard of is to support our families and our children so that they grow up with a sense of self-worth and some expectations for the future that enable them not to turn to drugs to deal with this kind of despair and alienation that is afflicting too many of our children. My colleague, Brian Coyle, will recognize that I come back to this thing frequently, but when we look to the problem of teen pregnancies, school dropouts, increased involvement with the juvenile justice system, involvement with a gang, increased use of drugs, the only strategy that promises a long-term answer appears to be dealing with the increasing difficulty the families are having in providing the kind of nurturing and support for their children. So I'm taking advantage of your question to make the

point that an ultimate drug strategy probably has to deal with these other larger social concerns. I would like to maybe ask Dick Johnson though if he would like to supplement an answer to this very important question.

MR. JOHNSON: One of the things the mayor has collectively had in past policies in the last couple years is a notion and we're going to try and not talk about more money because we have also talked about that in a number of policy regulations through the years. Your concern about the system is well taken.

In Mayor Fraser's remarks, written remarks, he referred to the concentration of AIDS cases in the cities and the written remarks listed a number of states. In Illinois, for example, 84 percent of the cases are in Chicago; in Washington, 76 percent of the cases are in Seattle; 96 percent in the state of Missouri are in Kansas City and St. Louis. For example, if you look at basically any state you will find that the concentration is in the major urban area of the state. However, if you look at the funding process of what federal government monies are put into the state, you will find that in Missouri, for example, it doesn't go to Kansas City or St. Louis, it goes to the state capitol and then finds its way several months later down to the local area with sometimes more strings attached. The money goes to community-based organizations, in some cases what the state thinks over what local experience and local imput may have about

where the money needs to go. So what the mayors have collectively done is recommend that the federal government fund cities directly, not all cities, of course, but those with the greatest need in terms of numbers of cases or numbers of cases and rate of infection. And there is precedence for this which we seek currently for funds in a small number of cities calling for over 2,000 cases plus the major source of cases within the state that limits to about 5 cities. And when this crisis began, of course, we had 3 cities falling under a category that was then announced as 500 cases. It was then New York, San Francisco and I guess L.A. at that time as well and built up over the years so that it was a crisis factor early in the beginning. Also we had 500 cases of it and now even more so this 500 level should be reinforced in direct relationship to the federal government.

DR. KONIGSBERG: If I could just make one point in reference to Kansas City in particular that I'm familiar with right now. One of the difficulties that I see in an earlier response to come against a response to this is the city boundries, the county boundries, and in some cases where it's able to cut across Kansas City, the state boundries, and at this point I think many of us are kind of at a loss to know how at least from a state perspective, both perspectives in an earlier response to the larger metropolitan cities and I'm sure here in the Twin Cities there is no opposition from Minneapolis

or Saint Paul on boundries in both counties. Has that been addressed at all, and what goes on in this kind of an issue because I know that's an issue to be raised in reference to Kansas City.

MAYOR FRASER: The coordination of the various units of government I think is one of the ongoing problems. I would like to invite Mr. David Lurie, our Health Commissioner, to help describe this problem in a variety of local jurisdictions that had a role in the health field.

MR. LURIE: Good morning, Madam Chair, Members of the Commission, a couple comments. One is that generally the response, and there is a seven county metropolitan area here in the Twin Cities so we do have alot of jurisdictions involved, seven counties and of course two major cities. The response and the activity throughout the AIDS epidemic have tended to be county by county and city by city but also I think there's a great deal of collaboration and coordination working together for a long time. One thing that I assume you will probably be hearing more about later today from the state health department is that we have here in Minnesota recently received a federal grant that's going to provide funding for a planning process, a collaborative planning process in the state of Minnesota that will be looking at future needs of AIDS patients in terms of treatments, support services, and so forth. And involved in that process are all the major health agencies

represented as well as community-based organizations within the state, all working together. My expectations of that is that we will be identifying from that process of what the future is going to be, what the capacity of our system is, and I'm sure some major gaps and shortfalls in that system in the years to come. And then from that process, the expectation will be, at least from my perspective, that with that information we will be going to the state and to the federal government seeking out resources to develop the future capacity for the system.

I would also like to respond, however, to an earlier question about complacency. Although we have a very good system in place here and I think we have been very fortunate in terms of resources, I believe there is a degree of complacency and I think there are some who assume that the message has been delivered and therefore maybe this is not so important now and we don't need to continue the effort. I think a shot in the arm is needed, I think we have got to continue to reinforce the prevention efforts, the education messages, and particularly I think we need to recognize, as I'm sure you're aware, that with the changing of populations that are affected, affected by this epidemic, we need to put in more energy into reaching drug abusers as we all know as the mayor pointed out, a primary intervention perspective as a prevention of people who get involved with drug abuse, but also working with those who are already involved as well as in populations of color.

It just is my opinion, and I think it reflects the view of a lot of people in the field, that we have relied on going from the prevention side of it and now talking a little more about treatments and support, we have relied on our existing health care system to absorb the disease in this arena and over the long-term I don't believe it's possible to sustain that. When we talk about drug and alcohol abuse there are a lot of volunteers and that's workable when the numbers are relatively small and it is a relatively short-term process, but this now appears to be very long-term and in order to sustain that, clearly we're going to need more. And I don't think it's reasonable to expect we can continue to absorb the needs within our current system. And I think also it's very good pointing out the weaknesses of our health care system; in fact, some major restruction in that system is clearly needed.

MS. AHRENS: I just want to ask a question or make a comment and ask a question. What we hear from the federal level is that the funding has plateaued. Now, if we accept that, that is the prognosis, some of us are wondering whether the money that is there could be better utilized by a new kind of mechanism to distribute that money, because it is in the pot, the different agencies, and it comes through to the state or different localities in categorical areas, some of which may not be the most needed in that area. And we at the local level think there may be a gimmick out there, that we are

in the best position to know what is needed to spend those dollars. Now, I guess I'm wondering if the Conference of Mayors has looked at the issues of integrated resources at the federal level that would then come down through the state and local units rather than the present categorical procedure that we are confined to?

MAYOR FRASER: Let me simply say that with everything else that we get from the federal government, I think it's my experience sort of being in both ends of this, where there are planning processes that are being supported and as David has indicated here we're about with the state to embark on planning efforts monies that flow through to the state and local communities that would enable then those plans to be implemented free of additional restrictions that are controlled at the federal level, would clearly be the most effective way to utilize the money.

The ability to plan at the local level, to take account of what we already have, the resources we have, the institutional resources, a variety of existing health coverages and so on, would enable the planning then to fit around that so that could supplement and reinforce those areas of which we don't have resources. So I think the combination of local and state planning and then federal money coming through without a lot of restrictions will provide us with the best outcome of that. I'd like to turn to Dick to see -- we've adopted some

policies and he could speak to that.

MR. JOHNSON: The Mayor is quite right in saying that the Conference of Mayors is in favor, I guess, overall, of providing localities with flexibility to deal with the funds as they best see fit as the best determiners.

However, our experience in some other federal categorical programs that have been block grants adopted in the '80s and late '70s is that in block grants the funds are already used and what actually comes to the localities we thought we may be a bit freer to use them for purchasing, is a lesser amount, and so we're caught between a -- whatever it is, a hard rock -- a hard place and a rock. So in theory, yes, receiving the same amount of money with more flexibility we would certainly be interested in, but again, block grants as they have traditionally been set up are not here to stay and although we may be involved with "state development planning" the decision is a state one on how those monies are spent, I would hope.

This afternoon you'll be talking to some of the city council people from Philadelphia and they will be talking about their experience last year in becoming a direct funding of the CDC, whereas before they had to go through Harrisburg, and what effect that has had on their ability to get funds quickly and to put them to the best of use.

MR. KESSLER: My only question is what success have the mayors had in terms of finding -- or developing

some of their own resources in the same way that they would for other conditions or in issues whether it be fire prevention or crime prevention and so on? I know there is a combination of federal and state dollars on the federal level as well, but it seems to be that there's only been a handful of mayors who have committed the local tax dollars to the AIDS battle and it's probably something that I think the Feds could go back in terms of your arguments and say, "You have no point to let the financial be inititive," and that's being set up in Minneapolis here. As far as the conference goes it seems that there may be need to do some education and leadership development there as well.

MAYOR FRASER: Part of it turns on the way in which officials view their responsibilities and David can probably speak to the number of communities that have their own health departments. For example, in Minneapolis one of the reasons I think we have several responsibilities is that we have our own health department and this clearly was a major health threat to the community. So the idea when you're putting some local resources as well as using other resources but I found it logical in order to respond to a variety of -- especially social concerns, is that if they have received county responsibility or state responsibility it's much more difficult. They lack sometimes institutional means to really move effectively into the field, and I don't know. Dave, you might want to add to

that difference that's across the country here with the organizations.

MR. LURIE: Well, there certainly are differences in terms of the level of responsibility and activity in cities in the public health arena and as the mayor points out they're not responsible for preparing anything, whether they see themselves as having primary responsibility or some other level of government. But I think also going back to the previous comments about the disproportionate share of numbers of individuals whose ties have been in the cities, many cities are not in a position financially to again absorb that and to be able to address that very disproportionate need and I think for that reason it's important that there be support from other levels of government and support to reflect a commitment at the city level either financially or in terms of leadership depending on the circumstances but I think it's unreasonable to expect cities to absorb the resource responsibility or commitment to the degree that the epidemic exists within the metro/urban areas.

MR. KESSLER: Well, I agree, I just didn't want -- I wanted to weigh the standard that appears to occur in many cities, the fact that when they -- it occurs when there is a place for investment whether it be a stadium, tourism and bureau, parks or underwriting or giving tax rebates, whatever, for industry and business. We have an investment here in terms

of the future as well. And often times AIDS isn't listed as one of those things you ought to be investing in is AIDS prevention. The issues are different, it's overwhelming in many ways as is the cost of care, and it is often overlooked when we talk about AIDS care. In hospitals, the AIDS epidemic prevention is often on the bottom of the list rather than at the top of the list in terms of preventing future costs. I get a little skeptical when I hear about jurisdictions and priorities and again I think it is a leadership issue that the United States Conference can help in terms of maybe motivating those officials to understand that certainly they've got to resist having the total responsibility but they need to be involved in terms of activating the system and showing local leadership.

MAYOR FRASER: Let me say I don't want to suggest that there's a lot of -- certainly in the larger cities the city governments have been very concerned and I think for the most part become actively involved, but I just -- having watched now with respect to different kinds of problems that have come along in a community, if the city government is not typically dealing with let's say a health problem and it's a county health departments and they're already strapped with resources to pay for their fire and police, and the notion of appropriating general tax monies and turning it over to another jurisdiction has rarely been appealing. But the development of planning, the support of -- especially nonprofit groups which

often do the best jobs as far as education and so on, but those are roles that the cities can play, and I think certainly the larger cities are very actively involved in this. Those are where the larger number of AIDS cases are being often found.

MS. AHRENS: I think Charles has the final comment because we are running late.

DR. KONIGSBERG: I want to place a hypothesis analysis, not a question. One of the things that I think we can get at if a person is commissioned to be part of this working group, which will look specifically to state and local health departments, if you really take the time to analyse our nation's state and local public health system I think what we will see in terms of testimony is what we see today which is the bright spots of this committee where the local governmental response has been excellent. And usually when you look behind that you can find a local health department that has been very much a part of that response. The various presence here is exactly the kind of thing we should see everywhere.

Now, I guess my concern is that I'm worried that nationally that there's a great unevenness at both the state and local levels dealing in public health which is the entire statement to the public to respond to this epidemic. I need to point out that many areas of this country just didn't answer at the time it was asked to, don't have local health departments in an organized sense that many of us were trained and raised to

think of, and I think that's something that we need to look at as we go through this and just to -- what we're saying here is just to the way it ought to be rather than to the way it is, everywhere. Then there's this dichotomy and I think that it talks a good deal about the integration across governmental lines on all of the levels, but across jurisdictional lines locally. I'm not sure how we get at that. Probably this seven county area has done that much and more of that type of progress than any place I've ever seen.

MAYOR FRASER: Diane, let me respond. This is a jurisdictional problem, one that's very much in my mind these days for a variety of reasons. Putting out resources, say to a metropolitan or an urban area conditioned on area-wide planning is the most effective way to cross jurisdictional barriers. The problem is if we get a middle-level beaurocrat who's administering the program whether that be the WITH Program or County Mental Health Program, instead of saying, "Now we've discovered somewhere else you can put some of your money," they usually don't have enough money for what they're already doing. We tend to become quite resistant, but if you can hold out and hear some new resources, we might even join hands. It's like the Marshall Plan got Western Europe started on intergration, it works for local levels as well. I reinforced Richard's point too that the larger cities, I think, if any federal legislation could be expanded to direct assistance then I wouldn't mind if

any police work would be an interdepartment plan to develop within the urban areas throughout the states. But getting money direct from the cities will improve our ability to address this problem, but I don't want to take that out of context. It clearly is needed for the long run and too much of the reaction so far has been a kind of emergency response. We need to recognize the roles now for a number of years to really get our ducks in the road and get some long-term planning.

MS. AHRENS: I really want to thank you for really, the scope of your testimony, it was just excellent, Don. The personal comments that you made, I think, brought out the depth of what we're really dealing with here and we thank you for that. Let me know next time you want your visa renewed.

I know that we're running late and I want to say that we're going to give our next presenter full time. We will be postponing our lunch hour until 12:15, and then we will postpone the beginning of our afternoon session until 1:15 so we'll have a full hour for lunch.

I'd like to welcome Senator Linda Berglin to the podium. I guess I should take a great deal of time listening to how any states do this and the fact that several of the national organizations representing various governmental jurisdictions show as their presenters leadership, political leadership from the state of Minnesota. It warms my heart. I've known Linda for a number of years, her leadership is extraordinary in our

state legislature, particularly in the area of health and human services. We welcome you to this hearing.

MS. BERGLIN: Thank you, Diane, and members of the Commission. It's an honor to be here to testify before you today. AIDS will be the most important health issue facing American society in the 1990's and very likely into the 21st century. Government has a responsibility to control the spread of the AIDS epidemic and to do all it can to facilitate the discovery of a cure for the disease, and to help victims of the disease obtain both the medical help and the social services they need. Efforts at attacking the many problems and issues surrounding AIDS are already underway in many states, localities and through federal government effort.

Some states and local governments have been in the forefront with efforts to develop policy, assist the medical community, meet the needs of AIDS patients and their families, form task forces at the local level, develop support networks and perform a host of other activities to deal with AIDS crisis in the communities. The National Conference of State Legislatures commends these states and localities for their efforts. As chair of the Minnesota Senate Committee on Health and Human Services, I am proud of Minnesota's efforts thus far to deal with AIDS. Working through our existing social service and medical care delivery framework we have funded special programs that target high-risk groups and notify partners of

AIDS victims. We also have dealt with the tough issues surrounding noncompliant AIDS carriers and the notification and testing of "first responder" emergency rescue personnel.

Last year we funded a pilot case management program with the goals of finding ways to draw on both the medical care and the public health systems in caring for AIDS patients, and finding the "gaps" in our overall system of meeting these patients' needs. We have mandated AIDS education in our public schools. Our goals have been to contain the spread of the disease while protecting the civil and privacy rights of AIDS victims and ensuring that those victims get quality medical care, mental health care and social services.

Despite efforts by Minnesota and many other states, it is the NCSL's position that the threat of AIDS to the health of the nation demands additional resources and work. In my opinion, states have a distinct role to play as we combat this epidemic. States must take a leadership role in implementing programs to address AIDS. This is the logical role for states to take given both the general history of public health matters and the way in which the AIDS epidemic will likely play out geographically.

In public health matters generally, and in particular in communicable disease control states have taken a leadership role in terms of program implementation -- undertaking tasks such as surveillance, identification of infected groups and targeting programs at high-risk groups -- to control the spread of the

disease.

The federal government has fulfilled a role of providing funding and technical assistance and directing resources to research for a cure. This "division of labor," if you will, has served us well in dealing with public health problems in the past. The AIDS epidemic begs state leadership because the incidence of AIDS will be different between states and different within states. It appears very likely that the AIDS epidemic will affect different geographic areas within states disproportionately.

Rural incidence, for example, will be smaller than incidence in the inner cities. Yet AIDS education and prevention efforts are still needed in rural areas as well as in cities. Each state will need to look at how the AIDS epidemic plays out within its borders and tailor its response accordingly. In the same respect, certain states likely will have higher incidences overall than others due to factors such as greater overall population or greater urban population. In short, all states will experience the epidemic but each will experience it differently.

State government should play a leadership role in implementing programs to address AIDS so that each state can address the problem as effectively and efficiently as possible. This is my opinion based on my experience in state government.

In looking at the types of programs to implement, it is

my strong opinion that states must ensure access to health care for AIDS victims. We know that without access to health care eventually public dollars will pay for this care but it will generally be at a later stage of the disease. It is appropriate to address this access in the context of addressing and insuring health care access for all persons in a state. While we need to be concerned about AIDS victims, I personally believe that we cannot be insensitive to people with other dreaded diseases who don't have health care access as well. I'm going to diverge for just a moment to stress that fact that federal reimbursements for those who are covered on federal mental programs is not adequate to meet the costs of those programs of care for those persons and that falls disproportionately on communities that have disproportionately high numbers of AIDS victims.

The federal government may be helpful in a number of ways in helping us address the issue of adequate health care. Federal coordination may be helpful establishing a risk pool for small employers or persons who otherwise cannot obtain health care coverage or in providing states with extensions from a RIFCA (ph.) to help promote state initives and experimentation in providing for uniform access to health care for all persons at the state level.

Along with access to basic health care states must ensure the existence and availability of appropriate treatment programs for AIDS patients. I believe such programs should include

alternatives to institutionalization such as community or health care. Since the spread of AIDS is high among drug abusers, education efforts must be coordinated with programs aimed at those drug abusers.

The NCSL has specific recommendations for combating the spread of AIDS. Education and prevention are the best defense since currently there is no known cure for AIDS. The NCSL calls for continued national debates on the many public health and public policy issues surrounding AIDS.

Primary consideration should be given to the immediate establishment of public and private education to reduce the spread of AIDS; the immediate development of fiscal resources for research, treatment, risk reduction, public and private counseling and testing; the immediate implementation of low-cost treatment and social services for AIDS and HIV-related diseases; and the effective and efficient use of all resources.

The NCSL calls for immediate, intensive prevention efforts directed at high-risk groups. The general public must also must be alerted of the nature and risk of AIDS through a campaign using all media and outlining the ways in which AIDS is transmitted and various methods of protection.

In terms of treatment and care of AIDS patients, the NCSL is particularly concerned with the development of humane, community-based alternatives to hospitaliation of AIDS victims, especially for children who have AIDS. Federal health care

programs such as Medicare and Medicaid should adjust their reimbursement mechanisms to reflect the need to provide alternatives to institutionalization and should support home and community-based care along with necessary social services.

The NCSL believes that innovative programs in the states and localities should be used as models by the federal government in promoting alternatives for the care of AIDS patients nationwide.

It is the NCSL's position that confidentiality of AIDS records is essential, as is nondiscrimination in employment, housing and insurance for those who test positively for the HIV virus for who have AIDS.

Some states have led the way in developing legislation and policies protecting the rights of AIDS victims. The NCSL believes federal initiatives should enhance and strengthen states' actions in this area.

In regard to testing, the NCSL position is opposition to federal legislation that would require states to test certain individuals for HIV infection. Such decisions should be made by state public policy makers and public health officials. If mandatory testing requirements are ever enacted, however, the NCSL believes the federal government must provide funding to cover the costs of testing, counseling, housing, treatment, and hospice care.

At the same time the NCSL urges individuals with a

history of high risk behavior, their special partners and pregnant women who believe that they have been exposed to the virus to voluntarily be tested for the antibody. Further NCSL urges federal, state and local governments to make testing sites readily accessible and the tests affordable or free.

The NCSL calls upon the federal government and the states to increase support for AIDS research, both basic and applied biomedical investigation, to improve prevention and treatment of the disease. Extensive epidemiological investigation is needed to assess the spread of the infection and monitor efforts to control it.

The NCSL supports the Food and Drug Administration's efforts to expedite the drug approval process for new anti-AIDS drugs and to ensure the safety of those drugs to the public. The NCSL urges that drug costs be kept as low as possible.

Finally, the NCSL recognizes that lessons about AIDS can be learned from other countries. It encourages international efforts to control AIDS and to make scientific advances available to other countries.

Education and prevention, treatment, assurance of civil rights, testing and research all are aspects of what must be our response to the AIDS epidemic.

It is my opinion that states will play a crucial role in the overall effort to control the spread of AIDS and deal with AIDS victims. State efforts should benefit from federal

coordination and funding and from local assistance in implementing AIDS-related programs.

Indeed, as the incidence of AIDS mushrooms in our country it is imperative that state, local and federal governments work together to address the problems and issues surrounding the disease if we are to be effective in dealing with the epidemic.

Again, thank you for the opportunity to be here today.

MS. AHRENS: Thank you very much, Linda. Perhaps I'll start with a question. As the Chair of the Health and Human Services Committee, I'm wondering as you look at the 1990's if you see issues that will emerge that we, the State, will need to address that so far really haven't been addressed in connection with the AIDS issue or as the AIDS issue impacts other health issues in your state?

MS. BERGLIN: Well, in Minnesota I think that unfortunately the increase of drug abuse is going to lead us to more AIDS victims than we have anticipated in the past. I think that one of the issues that we will need to deal with in Minnesota that will probably be a very difficult issue is how to most effectively combat this spread of AIDS among drug abusers.

I believe that this will be a fairly controversial issue for us to deal with since most policy makers in state government do not want to condone the use of drugs and it can be a very political volatile issue. It has been in terms of crimes in our inner city. So far we've been able to avoid that kind of

political contribution pretty much in regard to the AIDS issue. I mean, we haven't done in the past anything terribly irrational. Most of what we've done has been pretty much for the better. But when we get into the issue of drugs I think it will be a little more difficult dealing with that. I think along with the second wave of the drug epidemic, the third wave is the children and that we will have increased numbers of children infected with AIDS because of their exposure through their mothers as a result of drug abuse and the behavior that goes with that.

So I think those are issues that we will need to face and I think they will be difficult ones. I think also one of the issues, of course, is the whole area of access to health care which we're dealing with at the state level. We have a commission that has been formed to make recommendations as to how to provide for adequate health care. We need cooperation from the federal government in order to make those kinds of efforts on the state level possible. I don't expect we're going to see a national effort until we can have some successful demonstrations at the state level. And there are people -- especially now that we have more drugs and can count people at a much earlier stage of the disease. We have people in those situations that are employed and do not have insurance and do not have access to health care and certainly do not have access to the very expensive drugs that they should be using in order

to prolong their lives. And so that becomes part of the whole issue to make sure that states provide adequate funding and that's going to be a difficult issue because when we look at the balance of the needs of the general public without health care, again those who have chronic diseases, we have to make trade-offs because of the cost, unless we get some outside resources and so it becomes a difficult issue and one that we'll have to face.

MS. AHRENS: Charles?

DR. KONIGSBERG: Does Minnesota get mandatory reporting for HIV infections?

MS. BERGLIN: What do you mean by mandatory reporting?

DR. KONIGSBERG: Of positive HIV infections?

MS. BERGLIN: Yes, we do.

DR. KONIGSBERG: Has that been much of an issue in Minnesota? It doesn't sound like it has.

MS. BERGLIN: Well, it hasn't been something that has come before the legislature. I think there is some concern among some folks in the gay community about requirement, that there be a mandatory requirement of disclosure of partners to get tested and I think that's a legitimate issue that cuts both ways. Especially when we really want people to get tested early and they're reluctant to come in if they have to. We have to dispose of those sensitive issues up front. We have a clinic

in Hennepin County that has not necessarily done it. It hasn't been as adamant in enforcing those requirements as they should be. They are at odds with our own state health department about whether they have to be careful about that, enforcing that requirement.

MS. AHRENS: Thank you, Senator. I'm sorry that we were so late in getting to you but you're well worth waiting for.

MS. BERGLIN: Thank you very much and good luck with your work here.

MS. AHRENS: We're going to recess this hearing and we'll reconvene at 1:15 this afternoon. Thank you very much.

(WHEREUPON, a one hour lunch recess was taken.)

MS. AHRENS: We will call the session of this Working Group on the National Commission on AIDS back into order for the afternoon agenda. Our first speaker this afternoon is Councilman Angel Ortiz from the City Council of Phildelphia and if you would like to come to the podium. We welcome you here, welcome you to Saint Paul and Minnesota and glad to have you here and appreciate very much your willingness to respond.

MR. ORTIZ: Thank you. I passed the Mississippi yesterday.

MS. AHRENS: In Saint Paul we have the

Mississippi on both sides.

MR. ORTIZ: I noticed that as I crossed it. Good afternoon. The city council has made me wear glasses, I lost my sight. Let me say away from the notes that I welcome this. I think it's time that we began addressing the issue on a national basis. I think a lot more of this is going to be needed. We have an issue that is growing and it's tied to other aspects of urban and big city life and rural life as it begins to spread in the United States. I want to thank you for the opportunity to address this sub-committee. The plight of cities like Philadelphia in coping with the enormous challenges posed by the AIDS epidemic has yet to receive the attention it deserves or the resources to adequately manage this crisis.

Six years ago I was elected to Philadelphia City Council with a background in law and public advocacy. From my days as a law student at Columbia University and National Urban Fellow to the days spent as Managing Director of Community Legal Services in Philadelphia, I prepared to advance the position of those who were most forgotten in setting the public agenda. There is no one that has been as forgotten as the people who have AIDS. My assignment as Chair of the Health and Human Services Committee did not come until 1986, but it was clear that in that position I would be speaking for a group of Americans much more vulnerable than most, the poorest among us, the weakest among us, those least capable of putting up a sustained battle on

their own behalf. In other words, I have approached these duties as an advocate for public health programs, and I do so as I speak to you today.

The first thing we did was to call for hearings on the issue of AIDS in Philadelphia. At the time there was no program in the city health department and not only that, and aside from that, but when we first decided -- when I first decided that I wanted to have hearings the political reaction was very significant because it was a reaction of why do we have to talk about that. Why do we have to even bring that up? Is it because of panic? It is not the type of thing we should be discussing, and after all, our type of people don't get AIDS. It was a situation in which a lot of people said it is not political to have hearings on AIDS. Well, that's why we're here because it has to become political. It has to become because we have to get the political will to deal with the disease and the other aspects that create AIDS.

Everything that was accomplished in the city for People with AIDS was done through the efforts of community-based organizations. These were, for the most part, volunteer efforts that had risen as a response to constructively channeled anger and grief over the AIDS epidemic and the consistency with which it was ignored by by all levels of government.

At the time, the public and much of the government looked at this as an epidemic of white, gay and bisexual men. The

institutional forces at work did little to address the discrimination against this community -- and they haven't done that much in terms of addressing discrimination as such -- for the overt violence that was directed against it, much less concern itself with what had been determined to be a "gay plague."

In January, 1985, Philadelphia County had 112 cases of AIDS. By January, 1986, there were 231 cases. By the beginning of 1989 this would increase to 1,138 cases. The testimony I heard at that hearing was shocking. The snapshot that was produced showed an epidemic that already had a devastating affect on the gay and bisexual community across racial barriers. As a matter of fact, it was reaching deeper and deeper into the general population attaching itself to an already entrenched drug epidemic. Women and children were beginning to appear in the population of AIDS cases recorded at an alarming rate, and in my own community, the Latino community, the rate of infection was the largest with a 333.3 percent increase from the previous year; from 3 to 13, by 1989 the number had reached 108.

I generally caution people when I give out these statistics that there are several factors they should consider. One is that these are the cases that have been reported and do not reflect how many are still alive with AIDS. Even more alarming is that they only reflect those who have been identified as having AIDS, not HIV infection, not HIV disease.

These are numbers that if projections hold true range in the hundreds of thousands. Those who were identified as having AIDS were thought to have a 9 month-to-1 year rate of survivability, and AZT which had just been put on trials was available to a precious few. The number of doctors who maintained practices with AIDS patients was small, and those who had the expertise were rapidly facing burnout. Those who found themselves sick frequently found themselves subject to discrimination facing eviction, joblessness and homelessness. In many cases, people who had worked and been productive all their lives found that they had to apply for public assistance funds which all too often paid too little, too late.

For the poorest of the poor and/or those addicted to intravenous drugs, the epidemic reinforced their status of destitution in one of the world's most affluent societies. It was clear from the testimony that AIDS was not a gay plague but something that would change the way all of us live. It was clear also that one of the reasons for the delay in the response by government was sanctioned, institutional homophobia. Focused efforts must still be made to dispel such fears.

It was also very clear that this was not a white issue. Increasing incidents among blacks and latinos attested to this and we have exhibits in the back of this speech that will address it.

By 1990, some things have changed. The city of

Philadelphia now has the Philadelphia Health Department AIDS Activities Coordinating Office, an office I called for even before the close of the hearings. In the first year it operated, the city of Philadelphia funded the AIDS Activity Coordinating Office with $7.5 million dollars in local taxpayer dollars. This may sound staggering to you, but in a public health system that had no public hospitals, and without a clear national direction the city was left on its own to develop a response to a problem that did not stop at its borders. All attendant start up costs and program research and development expenses were paid for by the city. Frictions developed between those who had shouldered the brunt of the work that was now the concern of the City Health Department. There have been mistakes; but in the absence of interest from the federal government, except in the case of testing, the complex array of services needed to fight this epidemic were to be developed in an almost random fashion.

As situations presented themselves, they would be addressed. Beds were set aside at the Philadelphia Nursing Home for people with AIDS. Outreach and education have been started to communities which have too long been neglected. A series of services to people with AIDS was set up which provides a fragile network of care that still is insufficient to cover everyone who needs services. There exists now in Philadelphia an AIDS Consortium, a grouping of the city's community-based AIDS

organizations which having moved from volunteer organizations to professional organizations, represents the senior stakeholders outside of government for public policy analysis. Direct funding of the Consortium has helped to create new ititiatives for populations who remain underserved.

In working with these groups, my office has developed legislation which would require, by ordinance, that every business in Philadelphia be required to provide AIDS education in the work place; that discrimination against people with AIDS or HIV disease be made illegal by ordinance; and that those who are discriminated against be given a private right of action as a matter of course. I have advocated for additional monies for the AIDS programs in Philadelphia from every available source.

There was a time when Pennsylvania ranked 7th in the number of AIDS cases, but 37th in state funding. This too has changed. In addition to funding Philadelphia and other municipalities around the state, state money has allocated directly to the Philadelphia AIDS Consortium quickening the spend-down rate for the people who provide the bulk of the direct care and service to PWA's.

The stress of local and state government in bearing this burden is already taking its toll. In the latest budget year, the AACO budget in Philadelphia was reduced to $4.2 million dollars -- actually it was a little bit more than that, I think it came out to $3.7 million dollars; and again it was reduced.

And you have to understand because the nature of urban city budgeting, the nature of federal aid to the cities has been to reduced in every other level. So as we get less aid for housing, we increase homelessness. We have 15,000 people running around homeless. And we reduced the homeless budget in Philadelphia of $39 million dollars that the city of Philadelphia spent of its own taxpayer's money, the government could no longer afford to keep us spending it to $19 million dollars, almost half.

Now, there are people that are homeless, that are drug addicted that have acquired AIDS and are spreading the disease with no treatment whatsoever. We have been forced to begin cutting down in the aspect of infant and maternity care because federal funding is not coming. So we have a crisis in terms of where we are going to be spending the money.

We have just spent four weeks in Panama and we have spent more money, probably, in trying to catch Noriega, a two-bit drug dealer created and promoted by the United States, then we probably will spend on CDC monies this whole year. The stuntbomber is $500 million dollars, we used it to bomb parking lots to create a diversion in Panama. The CDC has a budget of $180 million dollars. The enemy is not Noriega, the enemy is right here. And that's the national interest in the United States, we are spending the money for that.

The last ten years of defense build up and reduced

revenues to cities have caught up with the advances in medical technology and an increasing number of people facing homelessness, drug addiction and AIDS. AZT and aerosol pentamidine have extended the lives not just of those with AIDS. Increasingly, we speak of people with HIV diseases and those who are HIV positive yet remain asymptomatic. Our ability to care for babies of crack addicted mothers has increased, but with it, the cost of care as well. In public hearings on infant mortality and on health and human services and homeless programs in the city, a macabre scenario has evolved making people compete for a limited amount of money which will decide the area of their lives in which they want to be healthy. None of these work in a vacuum, yet all are severely underfunded, with the prospects of additional reductions in the coming year.

The problem that we are facing is that Philadelphia and other cities have been trying to get ahead of the curve on providing services to those affected by the epidemic, and to do this, most other services provided by municipal government would have to come to a halt. How does one make such choices? Drug addiction has been widely seen as a metaphor for our times.

During President Bush's televised address on drugs he pledged $50 million dollars; $50 million dollars to the cities, mostly for increased law enforcement. Across 50 states this came down to precious few dollars divided up between even more cities. You know something, it is the consensus of most of the

police chiefs across the United States, finally, that making more jails and hiring more cops will not answer the drug problem. It will not and it is not the answer. Invading Bolivia and arresting Noriega as chain leader and some of the people said that now that Noriega is in jail we're getting a handle on the drug problem. He probably must be smoking some peyote or something because obviously the man is not very clear where the drug problem exists. You do not solve the drug problem in Bolivia or Panama. You solve the drug problem in North Philadelphia and East Harlem, you solve the drug problem in East Los Angeles, you solve the drug problem by getting the services to the people. Not by building the jails, not by our reinforcing and putting more of them out there.

Teenagers, who the President recognizes are greatly at risk to drugs, are also greatly at risk for AIDS. Those who learn to say "no" to a needle may not learn to say "no" to unsafe sex. In Philadelphia neighborhoods of Mantua and North Philadelphia, the teen pregnancy rate is higher than in some parts of the third world. Early outreach and intervention in these neighborhoods is critical, yet none is properly funded. You know, in North Philadelphia and Mantua, Philadelphia, we're getting diseases that we thought had disappeared. Tuberculosis is becoming a problem. Tuberculosis, I thought that was a disease that my grandfather used to have. I thought that had disappeared, but in the poor neighborhoods of this country it is

becoming a disease that is real.

Those who have become addicted to drugs also need new and innovative ways to break these addictions. Drug rehabilitation centers were not part of the President's plan. Across Philadelphia and in other citiess the family structure has been swept away by the drug epidemic. We read about 29 and 30-year old grandmothers who are taking care of their grandchildren so that in the luckiest of circumstances their own children can finish school; in the worst of circumstances, because their own children are addicted and incapable of doing so. There is a lot of attached testimony about the grandmother stories. It is increasingly common to find all three generations addicted. There's an article attached with testimony about grandmothers at 29. It's an incredible situation because what happens is that babies are having babies and those babies usually come out addicted and those babies are usually now today coming out with AIDS. If this occurs in the Latino or African-American population, there is an ever increasing chance that AIDS will perhaps be a factor in this household. Those who would choose the response to simply remove the child have not examined the high cost of maintaining the newest phenomenon of border babies, abandoned to the public health care system because the families can't take care of them and the expense is too great for all but the wealthiest of philanthropies to undertake. For the mothers of these children, there is little chance of escape. Society

and medicine look at them more as vectors of disease and less as the victims of disease. These are our constituents, and they need help.

To date, the federal response to this epidemic has been limited mostly to epidemiology, research and development. The federal dollars that have come to the cities like Philadelphia have come in the form of Health Services Resource Administration, HRSA, demonstration grants, and National Institute of Drug Abuse, NIDA, grants. While these resources have proven invaluable, they are limited in amount and in the finite nature of the money. This year, these two grants amount to $1.9 million dollars to the Philadelphia Health Management Corporation which has administered these grants for the last three years. The failure of congress to renew these programs and to add new dollars could result in a catastrophe in the provision of care and outreach to the poorest of Philadelphians and those most at risk for contracting AIDS.

None of this is to speak of the tremendous challenges ahead of us in producing services for the hundreds of thousands who are expected to test HIV positive, yet remain asymptomatic for up to ten years. While AZT and aerosol pentamidine may prolong life expectancy, without support and programs to assist them what kind of life can these individuals expect? For most people public assistance will again be one of their few resources. Some are people who should be able to remain in the

work force and continue to be useful and productive citizens; others need drug counseling and rehabilitation in a system which is already too overwhelmed to help. Still more will need the support and assistance at all levels of government that will allow them to continue to live their lives with the dignity and respect that is afforded to all Americans under the Constitution. The need to declare oneself destitute to qualify for life sustaining medication denies all of these options.

Programs need to be funded through the Department of Education as part of the federal war against drugs. The outreach and education to the school age population is critical if we are to get a handle on drugs, AIDS and teen pregnancy, all interdependent problems. Family Planning and education about sexual issues has become a necessity and must be introduced in age appropriate ways at the earliest opportunity. Bi-lingual and culturally appropriate measures must be taken so that all communities affected can be given life saving information and techniques immediately.

In Philadelphia, there are signs that the private sector has begun to move on this issue. The Philadelphia-based PEW Foundation after a very detailed study seems poised to step in and begin work with women and children. Such an effort cannot succeed without federal assistance. Drug treatment facilities must be expanded to include special facilities for women and children. People living with AIDS must have their rights

protected, and they should be allowed to continue their lives with dignity and purpose. HRSA and NIDA grants should not only be renewed but expanded so that we reach the populations that continue to elude us. The services in the cities must be sensitive to the individual environments in which they exist, but must also refine themselves to get the best for the citizens they benefit. The federal government is in a unique position to provide this kind of support.

I was asked to talk about the role of the city in this epidemic. The city of Philadelphia and other metropolitan centers are on the front lines of this battle. We have been, and it looks as if we will be for the foreseeable future. But, without the appropriate weapons, we may be fighting a battle which, if lost, will not stop at our borders.

Thomas Jefferson once said, "The care of human life and happiness is the first and only legitimate object of good government." I believe we are a good government, a government that wants to be the best for its people. This Commission in this sub-committee and the recommendations you make today will play a key role in seeing that my belief in good government holds true. Please don't prove us wrong.

There are some statistics in there that can give you a breakdown. I have Louis here from the Department of Health, Public Health and he's here to assist me in answering some of the questions that you may have.

MS. AHRENS: Thank you very much. I think the data in the back of your testimony is very interesting. I'm trying to read this correctly. Do I understand that in the city of Philadelphia the number of cases of AIDS would represent about 58 percent whites and 39 percent blacks? Is that what your first chart shows?

MR. ORTIZ: Yes.

MS. AHRENS: I wonder if you could just explain for all of us?

MR. ORTIZ: Yes. The rate in the black and latino community is a growing, almost geometric situation because of the intraveneous drug problems and so on.

MS. AHRENS: Could you just comment to us because we are trying to focus on the roles of the local, state and federal responsibilities, what is your interaction or relationship with the state of Pennsylvania?

MR. ORTIZ: State?

MS. AHRENS: Common Wealth, pardon me. Common Wealth of Pennsylvania?

MR. ORTIZ: Excuse me?

MS. AHRENS: What is the relationship between the City of Philadelphia in addressing the AIDS epidemic and the Common Wealth of Pennsylvania as you interact or relate to each other?

MR. ORTIZ: Well, as I stated, the Common

Wealth of Pennsylvania, our state government, our state legislature has been slow in coming around in recognizing that AIDS is a problem that has to be addressed. Two years ago the total state budget for AIDS was $350,000 dollars for the whole state. This has been increased now to $2 million dollars for the whole state of which Philadelphia will probably, maybe, be getting 50 percent of that because we represent probably 60 percent to 75 percent of the AIDS cases in the whole state; but it's $2 million dollars for the whole state. The city of Philadelphia at the urging of the hearings that I held and the urging of the AIDS and gay commmunity in the lobbying that was done, the recognition went from an allegated $2-1/2 million dollars to like I said in my testimony, $7.5 million dollars. And then because of the budget crisis that is hitting the metropolitan areas across the state we were forced to -- the mayor then cut it down to $4.1 million dollars that went directly from the City of Philadelphia. So you can see that we are actually at this point from the tax payers of Philadelphia -- and this is not a very popular in Philadelphia, it's not a political issue, it's an issue that politicians are very reluctant to support because it's identified with one basic community and now it's becoming identified with another community, the black and latino drug users and so on that's essentially powerless but it is growing and the city response has been much greater than the states at this point.

MR. KESSLER: My perception from other meetings that I have been at across the country is that your mayor has been pretty lax in his feelings and that you are the only public official in Philadelphia that has led on this epidemic?

MR. ORTIZ: I have been in the forefront, yes. You can see some of my scars. Yes, I have been in the forefront since I came into the city council essentially. Public health has become a major issue with me because the communities that I represent essentially are the poorest, are the powerless, the ones that receive less medical service than others.

MR. KESSLER: Of course the mayor was elected to represent all of the people of Philadelphia?

MR. ORTIZ: Well, you're always elected to represent all the people. Like Hubert Humphrey said, "Government is suppose to take care of those that cannot help themselves."

MR. KESSLER: Is it your sense that if the federal dollars were there the mayor would be more responsive?

MR. ORTIZ: I think if the federal dollars were there it would make everybody more responsive. I think then you have to begin looking at where you're going to put those federal dollars. If it goes through the state legislature and so on they become entangled in all those other issues by the

state legislature and by the time they trickle-down into the areas that need it, those dollars will be less and much more watered down than they should be.

MS. AHRENS: We want to thank you for being here today. We have many more questions but we know that you will be here tomorrow and some of those will get out on the table as we have a round-table discussion. Thank you so much for your presentation.

MR. ORTIZ: Thank you for inviting me.

MS. AHRENS: I would like to call James Smith who is with the National Association of People With AIDS.

MR. SMITH: Thank you Madam Chairman and Commission members.

MS. AHRENS: Before we begin, if I could just say -- and this goes to all the presenters today -- we hope that you won't be confined or held to the written testimony that you may have with you. We'd love to hear your comments on the substance of your presentation and if you feel comfortable moving away from the written testimony, please do so. It may free up some time for further questions.

MR. SMITH: Thank you for giving me the opportunity to present the perspective of one most directly affected by the subject of this hearing. I'll be briefly speaking on what I believe are major issues facing our country and responsibilities of the local, state and national level

organizations. Please understand that time today permits only a brief overview.

I'm here today speaking both from a personal and professional perspective. My professional background has been in substance use/abuse treatment and, in the past several years as an AIDS activist and consultant to AIDS service organizations and to a state of New Mexico department.

I was first diagnosed with AIDS in the summer of 1985 in Los Angeles. The diagnosis came as quite a surprise to me because I had long since ceased using IV drugs or practicing any other so-called risky behavior during the late 1970's. The virus has primarily affected my central nervous system, and of course, my brain. This is the first trip in almost two years that I have been able to take without having to rely on my wheelchair. Like many with HIV disease, I have "good days" and "bad days". Even though I'm currently in a "good day" phase, approximately five to six days out of the week are "bad days" which necessitates staying at home, frequently in bed, dependant upon my homemaker companion and nurses aide supplied to me by the Medicaid Waiver Program in New Mexico. Even on "good days" I must rely on 90 to 120 mg. of morphine to be mobile.

When I was diagnosed in 1985, I was probably infected sometime during the 1970's long before we even knew there was an AIDS virus. That's probably true for the majority of us who have either died of AIDS or are now living with the disease. I

was experiencing strange but minor infections, fatigue, weight loss, and on and on and on. The doctor informed me that I had less than six months to live. Obviously he was wrong. My first thought was, "I didn't get sober and clean just to die." For months my emotional state was one of confusion, shock, anger, depression, hopelessness, grief and fear.

Although my health is far from being considered even remotely good, the experiences of others with HIV disease as well as my own have taught me to cherish life. This disease has increased my need, my ability to help others to learn about AIDS. This has occurred in spite of the fear mongering of the Falwells and Dannenmyers of this country. From my travels and involvement with the National Association of People with AIDS, it has become painfully obvious that most of the country, if not the entire nation, does not have coordinated, collaborative and consistent social and health care services. The tens of thousands of those of us who are infected with the Human Immunodeficiency Virus are crying out for local, state and national leadership. The majority of the time we feel that no one is listening, that we have been abandoned by our government and society.

This commission has become the last hope for many of us. Hope that not only will leadership be provided regarding care and services, but leadership in prevention efforts so that others may not have to live and die with AIDS.

Since 1981, hundreds of my friends, former clients and acquaintances have died of AIDS. Hundreds more are sick or HIV positive. Too many of them are not "living with AIDS' but dying from the complications of AIDS. The responsibility for addressing AIDS-related issues and the services and care that are provided to us is for the most part are haphazard, inconsistent, isolated and not integrated. Then there is the tragic reality that AIDS-related efforts are underfunded or not funded at all. Consequently, the vacuum which grows with each new HIV diagnosis makes it easy to provide you with a litany of suggestions.

The HIV epidemic is much too large for national, state and local organizations and governments to address separately or without some vehicle for coordination and direction. Our attempts during the last eight years have been incomplete, results spotty, and victories few and far between. Innovative solutions are required if our institutions are not to be brought any closer to the brink of disaster or chaos.

One would be led to think from the testimony this morning that there is not a sense of urgency but successes outnumbering failures, that local, state and federal cooperation and collaboration are the rule rather than the exception, that social services and health care delivery systems are consistent throughout the country. That is not true.

My suggestions this afternoon are offered in the

understanding that if the past eight years are any example of the countries commitment to fight AIDS, very few of my suggestions will be taken seriously and even fewer will be tried.

First, we must come to terms with the multifaceted, complex and difficult to deal with lifestyles, ethnic and racial backgrounds, ages and socioeconomic statuses of those who have been affected by the infection in the past and will be in the immediate future. This entails several actions, initiatives, by all levels of our society, especially by all levels of government. One, HIV infected persons must be involved at all levels of decision making regarding AIDS-related efforts. Our involvement has demonstrated that service and care delivery will become more efficient and cost effective. Educational efforts usually are more effective when the audience knows, especially when they're teenagers, that the person who is talking to them will likely die from the disease. Two, we must realize and educate the public that all levels of society are truly affected by and responsible for addressing the AIDS epidemic. Three, funding sources need to understand that different populations in different geographic areas have different needs than those which might exist in the board rooms, executive offices and committee rooms in Washington, New York, and San Francisco. What we need in New Mexico is sometimes quite different than what people in New York need or Chicago or on and on. Second, if we truly want

people to come forward to be tested, then we must provide sufficient reasons for doing so. We must provide confidential if not anonymous testing which is free and easily accessible. Those who are willing to come forward deserve rights protections so that they do not need to fear losing their job or housing or treatment.

Financial assistance must be provided to help pay for the prophylactic drugs and care which can help maintain health and productivity. Creative insurance and health care financing and subsidies are needed. The AIDS Insurance Assistance Program in Michigan and the New Mexico proposal to fund local early detection and monitoring and treatment are examples. Unfortunately, the majority of HIV infected individuals fall between the cracks, not poor enough to be indigent, earning too little to be able to pay for proper care and for the drugs.

We must develop policies which encourage and promote the HIV infected person staying employed for as long as he or she wishes. Unfortunately, too many of us are forced into becoming indigent as the only way to afford and qualify for care. The country needs to know just how many people are HIV positive asymptomatic or have ARC or AIDS. Reporting techniques and criteria for diagnosing need to be refined and expanded.

Social service and health care delivery are a hodgpodge of resources and funding which vary widely from state to state and sometimes from city to city within states. More

coordination which encourages cooperation, collaboration and minimal duplication of services is required.

All of these actions require leadership which must begin with the federal government and the President. Without such leadership the cost of the savings and loan fiasco will pale in comparison to the cost created by a lack of national AIDS leadership. Leadership which is wise and possessing foresight requires the development and implementation nationally of consistently provided services of such programs like the Medicaid Waiver Program for People with Disabling ARC and AIDS. We must start establishing realistic qualifying criteria and income support levels for such programs as Social Security, Food Stamps, General Assistance, Energy Assistance, et cetera.

The average Social Security check in New Mexico is less than $400 dollars per month, the lowest possible rent for a single person in Albuquerque is $300 per month, the food stamps that they would receive for that average amount is less than $36 dollars per month. It is impossible to live any type of relatively quality life on that low of an income.

We must provide funding and encouragement for AIDS-related agencies within a metropolitan area to relocate into "AIDS Centers" where overhead is shared and clients may more easily access services. Such sharing of services has proven to be cost efficient and to most efficiently utilize existing dollars. This should be tied with a functioning AIDS

consortium such as the one one Philadelphia.

There must be accelerated efforts in researching, testing and releasing new and more effective drugs. The most effective organizations in the AIDS fight to date have been community-based volunteer organizations. Yet, insufficient funding exists for them to continue their efforts. Immediate and free or subsidized access to alcohol and drug treatment programs is crucial. Waiting lists around the country range from a few months to almost a year. Novel approaches to this age old problem are required, including needle exchange programs, free bleach kits, and non-judgmental education. IV drug use has been shown to be the vehicle to wider transmission, yet concrete outreach and treatment efforts are mired in moral issues. Increased funding for home-based care such as nursing, homemaker services and out-patient primary care clinics is mandated. In New Mexico, as elsewhere in the country, individuals must sometimes leave families, their cultures, and their support groups to travel long distances just to access services and adequate treatment. Expanded services and funding are needed for emotional and practical support for HIV infected persons, their families and significant others. Case management services have proven to be cost effective yet few states have initiated such programs.

People with AIDS and HIV deserve to be treated as multifaceted individuals just like everyone else. AIDS is not

everything in our life and whatever social and health care services as well as prevention and post-infection education that is offered necessarily must differ from region to region, person to person.

Our financial ability to access and pay for adequate treatment deteriorates with increasing symptoms. County indigent funds in rural America can be decimated by one AIDS case. Even in larger metropolitan areas, resources are far from sufficient. In my home county, the University of New Mexico Hospital which provides care for slightly over 50 percent of their AIDS and ARC cases in New Mexico lost over $900,000 dollars last year in providing care and services to those of us not covered by insurance or the indigent care funds. To afford aerosolized pentamadine many of us must import the drug from England at $30-$40 dollars a vial for treatment because we cannot afford the average cost in the United States of $150 dollars a vial.

Legal assistance to provide us with individual and class advocacy services is crucial to assure our access to services, entitlements and benefits, and to protect our human rights. For our nation to humanely address AIDS and HIV, we must cease focusing on who gets the disease and focus on the how. Our leaders must cease their search for the easy, immediate solutions and begin reassessing ways in which partnerships can be fostered rather than discouraged.

In closing, let me challenge you to provide the leadership. In a sense, you are as responsible for our care, our well-being, as the doctors who treat us. Your efforts can provide the guiding light by which American institutions and society rally in the fight against this terrible disease and the stigma that surrounds it. We know the solutions to the AIDS crisis. Various facets have been implemented as model programs throughout the country. AIDS could be stopped today if the nation only would recommit itself. Yet, how can the citizens of the nation know the issues, the suffering, the truth about HIV infection if our leaders, our media, our institutions do not lead us, do not inspire us and sometimes seem not to care. Thank you for your attention and for inviting me to testify today. Hope has been rekindled among those of us with AIDS and HIV with your appointment and with your recent actions. Thank you.

MS. AHRENS: Thank you very much, especially for making the effort to be here with us. Are there any questions? I would like you to comment on if you could talk a little bit about what the federal level, what federal funds should do and what state funds should do in terms of making the quality of life better for people with AIDS, and if you have a prioritized list of those thoughts?

MR. SMITH: I'm not sure about how prioritized the list is but we know the very topic would be the

ADA, The Americans With Disabilities Act. That is a beginning. I heard some people talk today about the need for rights of protection. If we go forward to HIV infected people with rights of protection then we would have a greater chance of bringing them in for early testing and early detection so that we know how it affects behavioral change or just to begin monitoring them in the hopes that we're following with medications and treatments that will keep them -- or slow them from passing on the disease which then would cut costs considerably. But there are very few reasons why people should come in. At a time when they should come in and be tested now because we have AZT and aerosolized pentamidine but for the vast majority of us with HIV infection we can't afford those two drugs because either our insurance is not covering any of it because we didn't make that much, or we can't qualify for indigent funds and consequently it's beyond our reach. We have to find a way of funding that. There's an AIDS Carrier Bill that is coming up in hearings by the House or the Senate or both, I believe, that needs a great deal of support to help get answers to some of those problems.

The other thing is for the federal government to finally take leadership in the AIDS crisis and AIDS epidemic. I believe the gentleman from Philadelphia tried pointing out -- or someone did this morning, that the local is governed by the states, the states counties, the state legislates the national government, the national government says it's anyone but them that's

responsible for the problem. The fact is that we all are responsible and we all need to be finding solutions for it.

MS. AHRENS: Thank you very much and I hope that you will be with us tomorrow for our discussion group. I now would like to ask Mr. A. Billy S. Jones from the National AIDS Network to take the podium.

MR. JONES: Members of the National Commission on AIDS, it is indeed an honor and a pleasure to have been invited to participate in the deliberations of this task force pondering the appropriate roles and responsibilities of local, state, federal government in the HIV epidemic. My comments will be based on my professional role as Director of Minority Affairs of the National AIDS Network, on having been a front line AIDS worker since 1983, and on input from other front line AIDS workers and organizations such as the National Native American AIDS Prevention Center, the National Council of La Raza, the National Coalition of Black Lesbians and Gays, and the National Minority AIDS Council. I also speak to you from the very soul of my existence and the memory of dozens of friends lost because of complications related to AIDS; from the recent knowledge that my youngest grandson and oldest daughter have been diagnosed HIV positive; and from having spent just last night in a hospital room of a homeless street addict who has been shifted from hospital to hospital merely because he does not have insurance to cover treatment for his diagnosis as a

heroin addict or as an AIDS patient; and from having worked with HIV positive incarcerated populations who often do not have access to early medical treatment but are often placed in isolation and without psycho-social support to cope with what they have learned to be a fatal disease rather than a chronic inanswerable disease.

Surely inertia is not an appropriate response to the HIV/AIDS epidemic, and surely punitive legislation to those considered to be in high risk groups or disenfranchised or disproportionately affected is not an apporpriate response; and surely decreasing the funding of community-based agencies or reallocating funds from other health and social service and human service programs are not responsible or appropriate responses to this epidemic.

The appropriate roles and responsibilities of the federal, state, and local government must be multifaceted, united, supportive of community-based efforts, and reflective of culture diversities and values. Governments must dig in for the "long haul". Not just for two-to-five years, or five-to-ten years, but for the duration of this crisis that is taking the lives of thousands of women, men, and children. Governments must assume leadership in this crisis. Governments must be at the forefront of research, at the forefront of prevention and educational programs, at the forefront of assuring that quality health care services are accessible and affordable to residents.

Leaders often must take an unpopular stance and try that which has not been tried. While preserving the fundamental principles of our Bill of Rights, civil rights, and human rights, governments must set the pace and incentives for the private sector to get involved and stay involved for the duration of this crisis.

There has been far too much blaming, finger pointing, and lack of clarity between various levels of government which has often resulted in inaction at the expense of communities throughout the United States, expense in terms of lack of meaningful and effective prevention programs, expense in terms of access to care and services for those with HIV-related illnesses, expense in terms of time and energy lost in planning for the response we need for the future.

Clarity and agreement, clarity and agreement on the roles of various levels of government are essential for appropriate responses from community-based agencies and the private sectors. How the federal, state, and local governments allocate monies is a message to others; thus governments need to provide a consistent message of leadership and to bring funding of HIV/AIDS programs closer to home, closer to the communities most affected, closer to the subcultures often alienated from quality health care and effective education messages. Community residents, members of subcultures and alienated populations, and racial/ethnic minorities must be involved in the total spectrum

of government decision making. And once is not enough.

The most effective prevention and intervention programs have been models developed by community-based programs; some of the most effective models targeting the most hard to reach populations such as needle exchange programs and the bleach distribution programs, condoms, IVs, DUs, not intreatment programs but are programs that are language specific literature targeting gay and bisexual men are often resisted and banned by government agencies and sometimes legislatures not willing to acknowledge that what is currently in place for the mainstream, is not working for the masses.

There is a need for government to be less restrictive of new and innovative programs which in the long run may prove to be more effective, more cost effective, and programs for addressing not only the HIV/AIDS crisis but other health and social issues of sexually transmitted diseases, unwanted pregnancies, and chemical dependency, and quality health care. It is ironic that as HIV/AIDS case loads in drug treatment programs, hospitals, hospices, and other systems increase, government funding is leveling off or being reduced. More attention must be given to primary health care and assurances that persons in all settings have access to quality health care, access to appropriate drug therapies, access to nontraditional reimbursement health-related services such as home care and nutrition programs.

Since prevention is still the only cure we have for HIV, governments must continue to support community-based prevention programs. Especially those programs which address sustaining behavior changes, which address issues of relapse prevention and intervention in terms of sexual and substance abuse behaviors, which address intervention as well as prevention, which addresses cultural barriers and attitudes which acknowledges the culture diversities of our macho culture in American society.

We cannot afford the luxury of addressing one aspect of the AIDS crisis: either education or services, either the gay community or the minority community, either health care or education. Governments must work with and support community-based efforts in designing multifaceted programs that assure intensive and effective prevention and intervention, educational and health care services. Also needed are culturally appropriate evaluation tools to assess the effectiveness of programs, to assure cost efficiency, and to design sound public health practices which do not create hysteria and which mainly safeguards for individual human and civil rights. Safeguards to offset discrimination stemming from homophobia, sexism, and racism must be instituted by all levels of government.

Those who do not have access to treatment programs and clinical travels, who have become homeless and jobless, who are institutionalized and then penalized would argue that AIDS is

not only a medical problem needing medical responses but also a social, economic and political problem reflecting the government's poor response to institutionalize racism, sexism, and homophobias. AIDS cannot be addressed in a vacuum or in isolation of other issues which create barriers to individuals responses to HIV/AIDS epidemic.

Some tough issues which must be addressed are issues of housing for persons displaced because of the impact of AIDS, issues of youth at risk because of drug and sexual behaviors, ever increasing chemical dependency issues and the need for increased and more effective treatment programs, the relationship of poverty to education and health care, the disproportionate impact, not only of AIDS but other health and social problems within racial/ethnic minority communities.

While there has been widespread call for early testing for early intervention for persons found to be HIV positive, few have addressed the fact that for the most part insurance and Medicaid will not cover medication for prevention. We are still living in an era of "wait until one gets sick" before we intervene. Leadership is needed on this issue by local, state and federal governments.

Much of the governments funding efforts have targeted the major epic cities and high risk populations. There is a trend to ignore low incidence and low prevalence areas and populations. Yet the proportion of HIV/AIDS cases is moving

beyond the epic cities of New York, San Francisco, and Los Angeles. Thus again, government must think prevention as well as intervention and fund community-based programs in rural areas, in low incidence and prevalence areas, and in racial/ethnic minority communities such as in the Native American and Asian communities in which HIV/AIDS cases are reported to be low.

Governments need to look at unique opportunities to train community leaders to address HIV/AIDS issues within their own communities. For example, the Native American tribal leaders must receive adequate training and orientation to the issue of HIV/AIDS in order to enable tribal health departments to educate at-risk populations; and recovering addicts, retired prostitutes, and ex-offenders should be recruited and trained to return to their former communities to target those involved in day-to-day risky behaviors.

Culturally specific research of attitudes and behavior practices within communities of racial/ethnic minority communities must be encouraged and supported by local, state, and federal governments. All research projects of racial/ethnic minorities should include significant representation from the community being observed, being assessed, being evaluated or being interviewed.

When I shared with my oldest daughter and my addict friend for whom I am a buddy that I would be talking to members

of the National Commission on AIDS and asked them what they would like me to say, they both said in their own way, please don't do yet another report of recommendations to be filed away on someone's shelf. Even as we speak, as we sit, as we listen someone is engaging in risky behavior that transmits a deadly virus; some child or adult has just discovered that they are infected; and some day and some nongay person has relapsed in what had previously been safer sex practices; and some recovering addict has relapsed and may share his or her running partner's work. As we speak, sit, and listen, my buddy, my daughter and my grandson awaits the leadership of their local, state, and federal government. The leadership they primarily get from community-based agencies who need ongoing support.

I thank you for listening to me a recovering addict, an ex-offender, and a gay man who wants to close with the message of Gay Mens Health Project in New York that "It ain't over yet," or from the streets of Washington D.C., "It be rough out there." Thank you.

MS. AHRENS: Thank you very much, Mr. Jones. Do you have any questions for Mr. Jones?

MR. KESSLER: Bill, I think that you need to be congratulated, I think first of all for putting forth the perspective of community-based organizations and the excellent job that you do with that and the extraordinary demand that your general staff has done in keeping all of those groups informed

of the technical assistance programs. I think that at the Washington Conference some of the commissioners that were there were very, very pleased when they decided to see what kind of conditions are provided on that front. When you talk about clarity and agreement my fear is that -- not fear, but my question is how do we get that clarity and agreement between community-based groups and various levels of government, especially when we're bound by so many restrictions or explicit education, and around things like bleach and needles and around moral values that are projected by men in congress and by others or local politicians on the communities most affected by AIDS; do you have any insights or any experience in terms of bridging that gap so we can get on with doing the work?

MR. JONES: When I speak of clarity and agreement, I'm not naive enough to say that -- to believe that we will be in full agreement on all the issues, but I think that the government agencies themselves need to be clear about where they stand, where that limitation is, and to not establish barriers that would hinder community-based efforts for addressing the issues. And I think that part of that effort will be establishing partnerships in ways that we have not established partnerships in the past. It may mean finding ways to work more closely with grass root community-based agencies that are willing to try new and innovative efforts. It may mean trying multifacet efforts in different areas. It also means

recognizing that there might be regional differences and approaching the same problem because they're not acknowledging that there will be cultural differences of ways of helping people approach the problem, but also evaluating that and not expecting instant results.

I mean sometimes we who are service providers get very much into assuming a pattern that addicts do. Addicts expect instant gratification, we expect instant success and we don't give programs enough time. So we often will fund demonstration projects or we will give two, three, four, five year fundings which really ends up being applied peer funding because we cut it to nine months. So we set programs up to start, don't provide technical assistance in terms of our organization development and program development so that they continue once the funding -- or the government pulls out on us. So it's those type of clarity and agreement issues that are needed on a community-based level and I think it's a setup, for example, to start funding a program and then suddenly cut loose. That part of what needs to happen when the government appoints those programs is also to provide them with various on-hand technical assistance so that they can survive beyond a limited period of time. This is not a three-to-five year crisis, this crisis is going to be with us for a long time.

So my response is multiple. It's the government needing to be more aggressive, more assertive, very clear about what the

various entities of the government will play -- will do on a federal, state and local level and to work with new partnerships.

MR. KESSLER: Thank you.

MS. AHRENS: Thank you very much. We look forward to your participation tomorrow with us.

MR. JONES: Thank you.

MS. AHRENS: Before I introduce our next speaker I just want to acknowledge that Eric Engstrom is with us. He's the new National Executive Director of the National AIDS Network and, Eric, we welcome you back to Minnesota. It's good to see you. Council Member Lori Palmer is here from the Dallas City Council and we welcome you to Minnesota, too, and back home, I think.

MS. PALMER: It is nice to be back home. I was born and raised in Minnesota and graduated from the University and then went to Texas as a Vista Volunteer and I never came back. Also I am a good friend of Scott Allen who is on the Commission and who I greatly respect for his leadership in Dallas and in Texas.

I will for the most part stay within the remarks of my written testimony. However, I may at some point elaborate on some of the political and social dynamics which have led to certain events and decisions to which I will be referring. I do appreciate the opportunity to be here today with you, value your

existence, and look forward to the results of your work.

I want to give a little bit of background first since cities operate a little different from each other within our states. We are represented on our city council by eight members who represent city districts and by three at-large. We are the largest city manager form of government city in the country so in essence the city council serves in a volunteer capacity. One of my responsibilities on the council is to chair the Housing, Health and Human Services Committee. In addition to that I serve on the board of one of our Dallas-based service organizations regarding AIDS.

The poplulation of the state of Texas is estimated at 17 million. Of that estimated number, 7,871 persons have been diagnosed with AIDS since 1981; 4,949 of whom have subsequently died from the disease. In Dallas County, with an estimated population of a little over 1.8 million, a total of just slightly over 2,000 AIDS cases have been recorded, with resulting deaths from the disease totaling 1,268. These figures rank Dallas second in our state to Houston. Additionally, it is estimated that between 20,000 and 35,000 men, women and children in our county of Dallas are infected with the HIV disease.

Dallas County is currently conducting a CDC funded household survey of 2,000 households and when completed this survey will provide us with more information and a more accurate estimate of the HIV positive population in our county. When the

results of this survey are released in April, we will all be better able to determine the magnitude of the problem facing our community.

In recent years, increasing demands have been placed on our county and our state to respond to the AIDS crisis. To respond to the crisis in 1988 the County Commissioners appointed an AIDS Planning Commission comprised of no small number of people, 141 members from the community representing all segments, I might add, of the business, civic, volunteer, church, and provider communities. I might add because it wouldn't be appropriate to single them out in my written testimony but we even had representatives of the Eagles Born (ph.) which is our arch conservative for the group with HIV funding. This commission was subdivided into seven groups which examined all aspects of the AIDS issues, namely: community Resources, legal/ethnical issues, public information, insurance, hospital, health care, and education. This comprehensive report -- and I'm going to leave a copy of it with you, addressed the issues in order to assist the county in really our metropolitan area, develop a unified and effective response to AIDS and AIDS related issues.

In the past three years, the city has received numerous funding requests for the provisions of direct services, case management and outpatient care, care for children with AIDS, or for children whose parents have been diagnosed with AIDS, dental

care, and respite care due to the gaps in our service delivery system and other sources of funding not being available to meet those needs. We have also received requests from nonprofit agencies for construction and renovation of facilities to support AIDS housing, clinical and research efforts, child care, and expanded food distribution. Requests for Community Development Block Grant Funds for 1989 totaled nearly $700,000. Of those requests only $147,000 in that year for funding, and $75,000 in reprogramming funds were earmarked for AIDS related projects. I might add that in addition to that we funded on a local level $400,000 in local tax dollars additional services.

As the number of diagnosed AIDS cases increases, we're finding certainly the demand for all services continue to rise. Even now, the need for health aides and skilled nursing care in the home is steadily increasing as AIDS patients begin interacting with the many nonprofit AIDS agencies in the Dallas area.

In addition to the demands placed on the system by the community, a major need surfaces, that of AIDS education. This education is especially needed by the minority population and high-risk groups such as adolescents and heterosexual females. In Dallas, 12 percent of the AIDS cases have been diagnosed in African-Americans, 6 percent in Hispanics, less than 1 percent in other ethnic groups, and 82 percent in Caucasians; 37 of the victims are women, and 8 are children. Recent figures from the

County Sexually Transmitted Disease clinic have found that of the men tested there, 10.4 percent tested positive for HIV, and 5.3 percent of the adolescent males tested between the ages of 15 and 19 were HIV positive.

Although there is no federal mandate that we provide AIDS awareness as is the case with drug abuse awareness, the City of Dallas has voluntarily initiated an AIDS Awareness Program. This program is operated in conjunction with the Dallas County epidemiologists, the city's personnel department, and the city's department of health and human services. The program is designed to provide factual information on AIDS, to dispel the myths about AIDS, and to address the subject of AIDS in the workplace.

In Dallas, community-based organizations and the public sector work together to address the needs of the community. Over 25 nonprofit and for-profit agencies work together with the city and the county to provide a variety of services to AIDS victims, their families, and to the community as a whole. These agencies provide health care assessment, crisis counseling, food, clothing, legal assistance, support groups, education, minority education, referral, outreach programs for the deaf, and a variety of other services. AIDS service-providing agencies come together at lease once a week to provide program updates, information on funding sources and discussion to determine what unmet needs continue in the community. This

system of collaboration is managed by an umbrella organization entitled the AIDS ARMS Network. A Robert Wood Johnson Foundation Grant awarded to Dallas afforded us the opportunity to address patient needs in a case management concept.

At the present time the City of Dallas, Dallas County and the State of Texas all play a role in the delivery of services to the community. The State provides supplies and education materials, as well as maintaining an AIDS Newsline in English and in Spanish for the hearing and the hearing impaired. The state also provides pass through funding to Dallas County from the Center for Disease Control.

The main focus of Dallas County is its AIDS education program. The program which at one time could respond only to requests for educational programs is now taking a more proactive stance in its educational process. The county staff is working to train volunteers and staff from other agencies to provide AIDS education programs. The county staff is also using more outreach to the high risk populations who do not ask for assistance or do not fully comprehend the fact that they are at risk to contract the disease. The City of Dallas assists the county program through the commitment of tax dollars to fund a portion of the county's education program. With Community Development Block Grant funds, the City also operates an AIDS education program for low income persons, with special emphasis on the righ risk and minority populations. Other programs

funded through the city's general fund and Community Development Block Grant funds include child chare for children with AIDS, case management for low income AIDS patients, health services and respite care. These services are provided through contractual agreements with a variety fo nonprofit organizations. Additionally, Community Development Block Grant funding is being used for partial construction of a clinical/research facility and a child care facility for children with AIDS or children whose parents have AIDS.

In order to address the AIDS crisis as effectively as possible, we need in our area a "Comprehensive Plan for the Future". The plan needs to be two-fold. A strategy of response to the HIV epidemic and a formula of financial responsibility by our social structures. One that includes prevention, education, intervention, counseling and testing, and treatment and care in comprehensive settings and not isolated as we now deal with AIDS afflicted persons. We need to approach this epidemic with clear and concise efforts that deal with specific needs while being able to maintain incorporation into an overall plan. A formula of financial responsibility that has enough flexibility to be utilized in various local, county and state settings is essential. Once a comprehensive assessment is ascertained, it becomes imperative for the federal government to lead in developing such a formula.

As we enter into the second decade of this epidemic, the

crisis mode of dealing with AIDS will transition into managing the disease as we manage chronic illnesses. We are already seeing some medical interventions prolonging the life of the HIV infected persons. Medical technology in the 1990s will require different interventions.

If persons with AIDS live longer lives and indeed live with a chronic ailment, like diabetics, hypertensives, and others, public health services will have to adjust their service delivery systems to include disease maintenance of HIV infected persons. Physicians and clinics in the private sector will also need to be trained for dealing with AIDS patients as routine procedures.

This change from a catagorical response to the disease to integration with all other diseases will become the focus of the 1990s.

Other issues for this decade will be financial responsibility, insurance coverage and social services for HIV infected persons.

Insurance companies will need to treat AIDS as they do cancer, cardiovascular afflictions or any other disease in their underwriting and coverage practices. Government programs like Medicaid and Medicare will need to revise their coverage as well. This will have to be done through legislative action in Texas since we have one of the most restrictive programs in the country.

Social service agencies will need to include in their priorities services to chronically ill HIV infected persons. Their need for social services do not differ from other disabled individuals.

To accomplish this enormous task in the 1990's, cities, counties, state and federal governments will need to develop innovative and creative models of coordination and collaboration to address this public health issue. Cities will need to increase interaction with state and federal agencies and legislative bodies to direct the changes in the system as they occur first in localities. Without these efforts we will repeat the same mistakes of the 1980's of not enough funding, gaps in services, lack of awareness, lack of education. We need to look to the future with more flexibility and less rigidity.

I want to make some comments to you about our state situation because I think it lends some additional awareness into how a state like Texas, which are extremely conservative, are addressing or not addressing the crisis. In 1989, this last legislative session, our legislature appropriated $23 million dollars for treatment and counseling. This is for the biennium, for two years. In 1987, in contrast, it only appropriated $3 million dollars and that was for education. However an increase it might have been, the $23 million dollars was less than 40 percent of what our state agency had requested from the legislature. The legislature very, very specifically through

its appropriation and its law singled out treatment and counseling and said that was the only two types of services they would fund. That had come as a result of what had been a bigger percent received this last summer in Austin which expected to go to the State and would only be using state tax dollars. To fund agencies in the nonprofit community-based sector they believe they will be promoting homosexual or bisexual life style. The only way they were able to achieve any kind of support for additional funding was to limit it therefore to two particular kinds of services, treatment and counseling and to prevent the state from contracting with any nonprofit organizations that had any affiliation with any gay-based organizations.

With respect to that, for example, we have recently just had a turn-down of state dollars in a comprehensive grant that had been submitted to the state by one of our umbrella organizations. It happened that that food bank was being furnished by the Dallas Gay Reliance and the state turned it down. So obviously we're still confronting a very conservative attitude and one that has channeled those dollars however small they are to very specific kinds of uses which will only go to municipal hospitals, clinics and local health agencies.

I will summarize my remarks at this time. I will be here tomorrow if you have any questions. I do thank you very much for the work that you are doing but would answer anything you would want to know at this time.

MS. AHRENS: Thank you very much. Charles?

DR. KONIGSBERG: You mentioned I think in the earlier part of your testimony something about a household survey in Dallas?

MS. PALMER: Yes.

DR. KONIGSBERG: As a public health official I obviously think it's very importantto learn the extent of our epidemic so that we know precisely what we're dealing with. Could you comment on your feelings about the importance of that and just how things are progressing in terms of completing that study and then comment on the controversies involved with it?

MS. PALMER: It's extremely important and I think the fact that we are doing it in Dallas -- if we can do it in Dallas we ought to be able to do it in most cities in our nation and I think for that reason it probably was sent to us in our state.

The interesting thing and some of the specifics of that is that when the county was approached, and the county is a conservative body. It is a body which is five persons who make decisions, three of them are republican and two are democrat. The county judge, who is a republican, was very much in support of this and was able through his public health officials to generate immediate response positively from, of course, the health delivery system in the city and in the county.

Where we ran into problems initially had to do with the

politics of the gay community. There was tremendous opposition to that by a segment of the community and unfortunately there was not an authoritarian response to that. There was an attempt to try to dialogue and provide more information and try to form some consensus because there were also segments of the gay community that were very much in support of.

Interestingly there was not to my knowledge any opposition to it from a conservative-based constituency from the city. And in fact, although I cannot tell you, Doctor, what the degree of response has been, I think it has been surprisingly high. And the fear, of course, was obvious that most people in random households surveys would be offended and resent being intruded upon and would not participate. That has not been the case. I tell you what really worked well at the beginning was the tremendous public education effort to assure people about the way it was going to be handled, how the information was going to be used and how it would not be used, what protection and securities were built into it, and more importantly, we had a strong leadership of the health department and the community behind it. So I really do hope that we in Dallas can give some credence to the value of that survey for other services in the future.

MS. AHRENS: I have a question with respect to what you didn't state in your testimony. I'm wondering whether you have AIDS education in the states education in the

public schools in Dallas or in Texas?

MS. PALMER: I won't be able to speak to you about Texas as a state, but, yes, there is, however limited, an AIDS education component in our public education system in Dallas. Fortunately the school board in Dallas has been very, very positive about including that. I do not know how it is received or for that matter how effective it is but I will tell you that it was put in place about two years ago at about the same time the county through its large task force and its multifaceted participation gave tremendous credibility to AIDS as a public health issue. The school district was involved in that task force and one chapter within that task force report deals directly with the responsibilities of the public schools and that did give, I think, some additional political support so the board of trustees would only have to be able to convince their constituencies that it was important.

DR. KONIGSBERG: I notice that your community was one of those that received a Robert Wood Johnson Foundation Grant. One of the things that concerns me about the demonstration projects, about the RWJ first is, rather obviously, what happens when the money runs out?

MS. PALMER: Which is about to happen to us.

DR. KONIGSBERG: Yes. Has there been any thought about how to continue those projects?

MS. PALMER: The AIDS ARMS Network which is

the group in Dallas that was funded right now has first of all become an independent -- it will become an independent agency of our community council which has been the umbrella organization for its victims, over the last year and-a-half has managed to put on its board a number of very effective fund raisers in the business community in particular, as well as in North Dallas where conservatism is known throughout the community. We have already -- and I'm on the board, we have already developed a fund raising plan which really will put in terms of transition some heavier focus on local foundations to begin to pick up a good share of that funding.

In addition to that, the business community has been very heavily targeted and there has been an effective approach in Dallas to deal also with major corporations. Our hope is that this organization will begin to be viewed by the business and corporate communities in Dallas as a service provider to their employees and that they have an investment in that service delivery system, and that what better way for them to help support that system is to participate in the funding. So that is the chief approach that they are at this point picking.

MS. AHRENS: Thank you very much. We appreciate your comments and we look forward to seeing you at the meeting tomorrow as well.

Some people are suggesting a break. It's 3:00 o'clock. Five minutes and then readjourn for our final four presenters

today.

(WHEREUPON, a short recess was taken.)

MS. AHRENS: We're going to come back to order. We welcome Commissioner Herb Stout from Wake County, North Carolina, that's the City of Raleigh, to the podium. Herb served on the National Association of Counties Task Force on AIDS and we really welcome him here.

MR. STOUT: Thank you Madam Chairman and Members of the Commission. First of all I would like to say thank you for meeting here in Ramsey County. I always wanted to see Diane in her native environment and the opportunity to be here in January. I want you to know that it's warmer here now now than it has been in North Caroline lately.

Diane, I want you to know that I called one of our colleagues over in Hennepin County this morning and his secretary answered the phone and she said, "Well, he's on the phone right now. Are you calling long distance?" And I said, "Well, I'm calling from Saint Paul, is that long distance?" She said, "Yes. Just a minute I'll get him for you." So it's good to be in this area.

I want to first of all thank you for doing this particular phase of your examination in your work, for studying the matter of the intergovernmental connection or the lack thereof. I think it's very important and I appreciate your turning your attention to that particular matter. I think we

have the potential if we work together to do a lot to help solve the problems in this country. If we just delegate and go off in our separate directions, then I think it's going to cause a lot of problems so I think it is the first thing for us to do.

You already have prepared comments from the National Association of Counties and so I don't have prepared comments to make but I'd just like to make a few remarks and then participate with you tomorrow.

I do want, however, to call your attention to this publication and particularly page 15 and to the 10 recommendations that we already have for the federal government and if we can just get those down we'll all be doing better. The 10 recommendations from the federal government. Most of the things that we've heard today I really think I need to say we have considered those because we did a careful examination before we put together this report. The 10 recommendations are not in priority order and I think it would be a good time to answer anything before the session tomorrow about those things that we think are most important of all and I will provide my comments about that also as we go through this.

I'm a little hesitant in coming to you because most of what I've heard about the situation comes from several of the panel members: from Diane, from Charles, from Pat and so really if you ask me a tough question, I may ask them to answer it. Being in San Francisco and Fort Lauderdale I've learned alot

about this particular situation. I may be pretty bold on some of the things that I say to you.

One of the things that we have found as we've been working with counties in the last few years, and this was something that was pointed out to us in San Francisco. Pat, you may be the one that did this -- it's that communities go through basically three phases with respect to the AIDS crisis and we do believe it's a crisis. And the first is denial, it's not my problem, it belongs to San Francisco, New York, Miami, but it's not our problem. That's the first phase, denial. The second is panic. Hello, we do have people with AIDS in our community, we do have people that are HIV positive. What are we going to do, it's now here at home? And the third phase forces us to try to figure out what to do and to do something about it is the third phase. We have anticipated that in the National Association of Counties, we had our task force and we have issued our report and this is not a report that just sits on the shelf.

We did, in fact, begin the effort to develop a task force to settle things down. We felt like we had a short-term mission, we did our job, we prepared our report and it was time for us to go home. What we found at our last meeting is that we had new people showing up to question that, to question the wisdom of that, to say, "Wait a minute." Los Angeles had already entered their second phase, they were in the panic phase, what will we do?" And they were wanted us to continue

our work because they needed to know what we had found out and they wanted to take it back to their communities. Everytime we have a meeting, a national meeting or a legislative conference, we have more and more counties that now are very suddenly interested in the problem and want to know what to do.

I think as people pointed out because sometimes they don't get an appropriate response from counties it's not always because the counties don't want to respond but they just haven't gotten to phase three yet in their involvement of this particular situation. And counties have a lot on their agenda, they have a lot of tough problems to face, they have alot on their agenda. It's certainly a matter of a lot of counties that they have not yet turned their attention to this problem. It is my prediction that they will. We are finding that more and more are beginning to face this problem and they are looking for help. They are looking for help in the National Association of Counties and we're prepared to give them that help.

We are prepared through workshops, we are willing to answer their questions, the support from our staff, it's not the case that we can send out full-time staff person all the time to the counties. But we have prepared this report, we have commissioners who are there and other members of the task force who are prepared to assist counties when they need assistance. We have the proper response to the AIDS crisis so we are becoming more aware and it is kind of like a ripple across the

water, it is coming to our counties now. I don't think that they should necessarily be accused of being insensitive although that's clearly when you have -- is it 3,107 counties, there are some that are going to be that way. It is a moral issue when it's not being done in phase two and phase three, they are still in the denial phase so I think it is a matter of we refuse to respond and we will not respond.

I want to make a couple comments about some of the things I've heard here today and some of the things that we had heard on our task force. I don't meant to be harsh on some of these things but I think that we need to face the realities in our country about what we are going to do, what we can do and how we're going to get there. Alot of times -- you have to start from where you are instead of where you would like to be. I would like to say we have heard a lot of comments about the problems that we haven't helped here, we've talked about infant mortality, we talked about Noriega, we've heard about the problems of Europe and different things and I don't mean to make light of that in any way, shape or form, but what I'm say is that we cannot wait to solve all of the local problems that we have in this country before we get on with doing something about AIDS.

I think what we have to do, particularly with respect to this task force, is we need to identify there's a few things that are most important that can help us all the most and do

those in the most effective way. Through the existing structures, if necessary, rather than going around it but in whatever ways you can do that you can be most effective.

There are some things that can really help us in this country that this commission can do without trying to solve all the problems that we currently have. We just aren't going to solve the problems with the health care in our system first and then respond to AIDS. It's just not going to happen. So I think this commission needs to take the leadership in that, as well as the counties. These are the things that are most important that we do.

The second thing that I would recommend to you is that you also assume that counties have a very important role and that you delegate what is needed and you expect counties to perform and even structure yourselves such that counties are encouraged to do the things that they can do and they need to do. Particularly in the area of education. I think counties can do a tremendous amount in that area. I often chuckle at all the political hobnob that we hear about education in this country and where it comes from. You hear an awful lot from, for instance, the Department of Education, I think we still have one. And you hear in the area of our state about the Department of Education, yet never has a child been educated in our state Department of Education or our federal Department of Education, it doesn't happen. It happens in local school systems. It

doesn't even happen in the superintendents' office, it happens in local school systems. I think we need to be cognizant of that.

If we're going to help people in this country, it's going to be in counties and in cities if that's where it's appropriate, and in the organizations where we meet people face-to-face. We need to structure ourselves so we can be helping those organizations that are actually working to solve our problems. It's very important that we do that. So as a condition I would recommend that you do these things that will help us out as counties, that we define that role that you expect counties to perform, that you expect cities to perform, put that responsibility on their backs. Find some ways that you can figure out whether they're doing the job, and then go help them out and do expect that counties will be a partner in whatever it is that we do in responding to this particular crisis.

I want to just reiterate a couple of things that have been said over and over and over again today and I don't think it hurts to say them over and over and over again because they're so important. We need money. I would rather have money from the federal government than for the President to stand up and say all these great things that we do not want him to say. I would rather have money because if you give me money I can do something with it, I can't do much with political rhetoric. So

give us the money, we need the funds.

The second thing that has been said to you is that we need flexibility. We need that flexibility. Tell us what you want done, tell us what the outcomes are that you expect but don't tell us how to do it. Just give us the resources to do it, help us find those resources. We're already coming up with our own resources to do that, but give us some flexibility, tell us what you expect.

To make an example of that, don't tell us to go educate people, tell us that you want people educated. Now, there's a difference there, that's not just semantics. There is a difference there. Tell us that you want people educated, not that you want us to educate people. In other words, don't come down and look to see if the program have been set up, come down and look to see if the people understand what's going on when they get out of that program. I think that's the important thing to do.

There's certain things we can't do in our own midst, research in the medical field, we're just not prepared to do that. However, I really would like for you to really push the federal government and to have them put more money into research, to monitor that research, put it on the fast track. We see some real problems now and we've been reading in the press that there's been research on AZT that indicates that if you were to reduce the dosages of that there are a lot of

possibilities for that, that early intervention is very important. Yet the federal government has not completed their testing on that and doctors are obligated to use that dosage and therefore the toxicity problems still exist with AZT. Until the federal government has made its move and says it's okay to reduce the dosage I think we've got to put that on the fast track, and understand the liabilities of that. I think we've got to accept that we've got to do that, I think we need to push the federal government to really do its best in that area. We've put money into research, I know that's got to be done at the federal level.

I don't know if you can encourage the private sector to do that, I don't know if you can. The word is around that there's going to be a big research facility in our area and I hear from those people occasionally, they're very defensive at times about this response. They've assured me they're going for good causes, I believe this. I really would like the federal government to ensure that if there's any way possible. Those are the big things, those are a few of the big things. We have ten items on our list, I would encourge you to look at those and we can look at those again I'm sure tomorrow. As we look at them again, I'm sure there are a number of those things that have been mentioned before, but the research is very important and the flexibility in utilizing the resources that you give us is very important. I would ask Mary Williams some really tough

questions. She's the staff person who has assisted us on our commission since it began and is a very knowledgeable person in that regard. If you would permit me, I would give Mary the chance to say a word or two if she would.

MS. WILLIAMS: Thank you very much. I really can only support what Herb said. I think the people who don't expect it as critical to organize the functional role of local government, and I think the federal government does not do that now in its health care programs, there's a number of ways you can do that. One is by the way you direct your fund that you get and one is by the administrative flexibility in the use of those funds, and by you I mean the federal government. I think those are critical aspects that will influence the whole health care system in this country. If they are pushed in terms of -- in response to the AIDS disease, they can't help have a broader impact so I urge you to pay attention to those things.

MS. AHRENS: Commissioner Stout, you're from North Carolina and I don't know a great deal about the health care system in North Carolina so I'm wondering if you would just comment on the relationship of the county system to the state system? Maybe I should ask, if you were to dream, what would you want the state of North Carolina to do in addressing this epidemic that would help the local counties?

MR. STOUT: I'm afraid there are reporters in the room so it might get back to North Carolina so I'm not sure

I should say. That happened to us in Cincinnati. I made the front page in the Cincinnati newspaper and somehow it got back to North Carolina. Basically I think that the states role could help us if they can deal with discrimination issues, city housing issues, anti-discrimination issues, if they can -- because we can't pass laws to do that sort of thing. That's where they can help us the most. Beyond that we need funds and we'll be glad to take them from the state, we'll be glad for the federal government to chip in, otherwise we have to raise our main property taxes so that's really the role the state would take. If you can't take the first approach, sometimes there's a different approach.

North Carolina is more progressive than you might think from some of our national representations, but you have to realize that sometimes the best thing to do is not to put it on the front page. For instance, our county it rarely makes the front page, we don't want it to make the front page. We're doing good things quietly without a lot of hoopla and that works the best for us in North Carolina. So that is the role that the state could take and it would be most helpful to us; funding and to take care of the discrimination issues.

Our structure is such that we are jointly funded in our health efforts by the federal government and the state government and the local government. We appoint a board of health that employs the health director and an administrator for

the problems in North Carolina and so we have substantial state funding, we have local funding and we have federal funding but we do appoint the board of health and we do so in our county and we have in fact made a significant response to the AIDS crisis.

We appointed a task force in the very beginning and this is all done by our health department, we have an excellent health director, we have employment policies, we treat ourselves as employer as well as leaders in the community and so we feel like our policy should be a model for private industry in our communities. We have a case management system, we also have a administration project that we're working with the University of North Carolina. We got some money from them for minority youth. Our minority population is over 20 percent in Wade County and so we are working with minority youth in that project. We're doing --there's numbers of things that you see listed by other categories, we're trying to do that and we're trying to stay ahead of the situation and we are making progress.

I will tell you one more story. When I got back from San Francisco -- that was my first indepth exposure to the particular situation. I guess I read about it in the newspaper like everybody else but visiting San Fransisco General and visiting the particular programs that you have and talking to persons with AIDS wasn't very familiar to me. Within 30 minutes after I got back my son walked through the door, he's a sophomore in high school and I thought, "I'm going to find out

what we're doing in Wade County." So I stopped him and I said, "Let's have a little talk." I asked him a lot of questions about AIDS, very specific questions, one of the things we'd been told is that you talk about the things that you want to talk about and so we did. I asked him very specific questions. He didn't know the answer to the one about bleach, he didn't know what bleach was but then I didn't either until I went to San Fransisco and found out what it was for and why you use it. That's the only one he didn't know and the good news to that is I asked him, I said, "Where did you learn all these things?" And he said, "Well, we've had it in our health courses." He's a sophomore in high school. It had already been done without the county commissioner or anybody else saying do it. Our health director of our school system and the superintendent of our school system had gotten together and decided this was something they needed to do and did it. It never made the newspapers, it was not a controversial issue. They just went out and did it and so that's the approach that has worked for us in our particular county.

MS. AHRENS: Are there any questions at this time?

DR. KONIGSBERG: Just kind of a comment more than anything else. I think it has some relationship to the National Association of Counties. I think the partnership between the elected officials and appointed public health

officials is real critical. If you listened to Commissioner Stout, you heard at least a half a dozen times about how that works on a day-to-day basis and I think that many of the most successful programs work that way. I think NACo is to be commended because they've really picked up on a number of significant health issues over the last five or six years and AIDS being one of those. Commissioner Stout, I do want to ask -- I know for a fact Wade County is not rural --

MR. STOUT: This is true.

DR. KONIGSBERG: -- but it isn't far from rural and one of the things I'm trying to sort out in Kansas right now is exactly how to approach the AIDS problem in the rural areas.

We've heard, as we always do, the testimony of people who are heavily impacted in the urban areas or from fair-to-low incident urban areas that have a lot of resources. I have been asked questions by reporters about what are you doing with 18 AIDS cases in 100 rural Kansas counties? Frankly, I don't have a clue as to how to answer that kind of question, but I was just wondering from your North Carolina perspective and talking to your fellow commissioners who work with NACo how this is being looked at?

MR. STOUT: You're right, Wade County has 400,000 citizens and we have 12 municipalities and 160 square miles and we're really not as rural as we used to be. We've

still got some tobacco farms and things like that but not a lot in Wade County. I will send you -- I saw a presentation of a demonstration project where they're working with rural AIDS -- I'm not sure where it was --

MS. FRANK: Was it Del Ray?

MR. STOUT: No, it wasn't Del Ray, maybe it was. I don't recall exactly where it was but I'm going to give you the particular project that I'v seen. Maybe it was at the University of North Dakota, I can't remember exactly where it was. The particular strategy lies in the one strategy group they're trying to do this with and you can help me by -- I don't remember where I got this so I'll have to go back and find out who is doing this particular research, but there is a research project designed strictly for rural areas, small rural areas, and what they have done is set them up with a counselor and they have identified people in small communities, I mean small communities of 1,000/2,000 people. In Wade County we have, of course, communities as small as 500 people, in North Carolina we have that. And what they have done is to network there through counseling in regular contacts over the telephone. And they have done conference calls of no more than I think four people plus the counselor is the way they do that. They have registered physicians assisting what fails to be the concerns of the health departments so that you have one person in this community and one in this community and most of the people, as

they have reported the results, have the AIDS virus in their community. They have AIDS but nobody knows it accept the doctor because they're afraid of the discrimination situation so nobody knows. And they don't have any peer support groups at all and therefore they can't live with this. And they will have meetings periodically but that's all on a voluntary basis. They have to agree ahead of time to come to the meetings and they use different names over the telephone so they really can't be identified by anyone other than the counselors. So their approach efforts has been very successful in networking approaches that way. Now, as far as delivering sources to them it's been through the judicial systems. This is a mechanizm of helping to keep their alternative care to supporting their families in order for them to access the things that you might get, the type of support that you might get in a real urban environment.

DR. KONIGSBERG: So in other words the counties and the communities are networking and getting together and also using telecommunications?

MR. STOUT: That's the only innovative strategy we've got in Wade County.

DR. KONIGSBERG: I think that's one of the best types of things that have been looked at for rural health care. In a larger sense it's going to require real rethinking of how we deliver health care and perhaps rethinking about how

we look at care for families too with AIDS.

MR. STOUT: Well, we have some -- we have a new environment in our country and we need to take advantage of it and we don't do that very well in government, and that being improved transportation and improved communications and we need to apply that to our service delivery systems.

MS. AHRENS: Thank you very much, Mr. Stout. Commissioner Mary Madonna Ashton from the Minnesota State Health Department is with us and we welcome you very much.

MS. ASHTON: Thank you. I'm truly honored to be here and to be participating tomorrow as well. We in Minnesota's Department of Health have determined that the role of state government in the HIV epidemic is surveillance, leadership, policy development, development and coordination of resources, and the provision of technical assistance. Therefore, I will describe each of these areas and illustrate how we have implemented these in Minnesota. I will also suggest that the challenge to this Commission, and indeed to all of us, is to devise the means of assisting communities in responding to the HIV epidemic in ways that are appropriate for those communities. A further challenge is to determine funding priorities and methods for resource distribution that recognize the differing needs of communities throughout the nation for prevention programs and service delivery.

So let me talk first of all about surveillance. Any

disease intervention strategy must begin with an assessment of the magnitude of the problem in the population and an identification of those within the population who are at highest risk for acquiring disease. Therefore, accurate baseline data on disease occurrence are needed. In addition, ongoing surveillance data are essential for monitoring trends over time.

The state is the level of government charged with the responsibility of collecting data on the occurrence of various communicable diseases, including HIV infection. These data are used not only at the state and local level, but are also forwarded to the federal government for evaluation of national disease trends. This responsibility has been controversial because issues relating to the HIV testing, reporting, and special studies have not always been well received or fully understood by certain groups at risk of disease. Nonetheless, without surveillance data to evaluate the effect of various interventions, resources for prevention and services would be nonexistent.

As the AIDS epidemic continues into the 1990's, accurate surveillance data both at the State and federal level will be critical if we are to direct our limited state and federal resources in the most effective areas.

The Minnesota Department of Health has implemented active surveillance for reporting of AIDS cases and all other cases of HIV infection, regardless of a clinical presentation. In

addition, the department is an active participant in special HIV seroprevalence studies being funded and coordinated by the Centers for Disease Control.

Now as to leadership. Data about the HIV epidemic are of limited usefulness if not utilized to plan, implement, and evaulate programs. State government can plan an important role in convening representatives from various target populations and service organizations to review and analyze the data and to plan prevention and service delivery programs.

Minnesota has convened what we call a Commissioner of Health Task Force on AIDS, composed of representatives from target populations, community groups, medical organizations, and government agencies. The state has also convened an Interagency AIDS Issue Team composed of representatives from 30 state agencies, an Interagency Committee on AIDS Health Care Financing Issues composed of state agencies financially impacted by AIDS services; and a subcommittee of the State Community Health Services Advisory Committee which is a group representing local public health agencies from throughout the state. The Minnesota Department of Health has provided staff support, data, and technical assistance to these groups to ensure that meaningful and scientifically sound recommendations and plans are developed.

The Commissioner's Task Force on AIDS has developed a "Statewide HIV Risk-Reduction and Disease-Prevention Plan" which

pertains to planning behaviorally-focused prevention programs. It also makes numerous policy recommendations ranging from guidelines for HIV testing to recommendations regarding children with AIDS attending schools and day care.

A newly formed Commissioner's Task Force on AIDS is currently being developed and will address services for people infected with HIV. Minnesota has found these task forces to be invaluable in developing consensus around policy issues and public health interventions appropriate for our state. These, of course, are based on our experience and care for the disease. Although the work of future task forces may be different than in the past, there will continue to be a great need for these types of groups as new issues and challenges pertaining to the HIV epidemic emerge. In the future, each state will need to develop a response that reflects the different disease conditions in its territory. We have analyzed the impact of AIDS on Minnesota by different geographic regions, utilizing a measurement technique called "years of potential life lost." A copy of this summary is included with my remarks to illustrate this point.

As you can see on the chart on page three, AIDS will have minimal impact on Greater Minnesota, which is primarily rural in nature, when compared to other causes of death. This is not to say that AIDS will not be a problem in such areas. We've already heard one case of AIDS in a small town can be as traumatic for that community as several hundred cases in a large

metropolitan area.

Conversely, the impact of AIDS in Minneapolis has been, and will continue to be, devastating. The variability in the impact of AIDS by geographic region in Minnesota is illustrated in Figure 1 which is attached to my remarks. Thus in Minnesota, the response in Greater Minnesota will be very different than that in Minneapolis; however, both communities need to respond. At the state level we can assist local communities in developing their response through providing appropriate leadership and guidance.

Now onto policy development. The state's responsibility in policy development flows from the planning activities described above. The guidelines and policies developed by the Centers for Disease Control have been key to the foundation of Minnesota's policies regarding transmission, control, and education. Information from the CDC allows states to learn from each other their experiences and to develop policies that are based on the best scientific information available.

Frequently community acceptance of a policy depends more on a person's ability to explain and defend that policy than on that policy's scientific correctness. The state's role of policy development must include both policy dissemination and training agencies and organizations in policy implementation.

In Minnesota, we have conducted extensive training with all local public health agencies on AIDS policy development and

implementation. This is particularly at the local level. The Minnesota Department of Health developed a policy workbook that describes policy areas and issues with citations as background information. This was not a book of policies that could be adopted without further discussion by worksites, community agencies, or health providers. Rather, it was a model for developing policies to fit each organization's special needs, and it required active participation of the organization developing the policies. This philosophy is consistent with my earlier remarks on devising the means of assisting communities to respond to the HIV epidemic in ways specific to their needs.

Now on to development and coordination of resources. Coordinating the types and kinds of HIV funding is a challenge, but one that is not unique to state government. It is not uncommon for a state agency to receive funding from a variety of sources for one program, and indeed it is not uncommon for multiple state agencies to receive funding from a variety of sources for this same program. HIV is no exception. Minnesota has been successful in securing funding from the CDC, the Health Resources and Services Administration, and the state legislature.

States have provided and need to continue providing substantial resources for AIDS. In fact, Minnesota provides more funding than the federal government for prevention activities in our state. This state funding has allowed us to

move faster in getting programs established than if we had to rely solely on federal funds. It also allows the state to implement a state plan rather than a federal plan.

I must comment here that our state legislature has dealt with the AIDS issue in an extremely responsive and responsible manner. I think we have gathered that from listening to Senator Berglin this morning. When funding was needed, the legislature responded in a timely manner. When policy was required, the legislature responded. Just as importantly, when misguided policy was not needed, the legislature was not afraid to say "no". A number of my colleagues in other states cannot say the same thing. Our legislature has allowed us to spend our time fighting the AIDS epidemic, rather than fighting misguided legislation driven by AIDS hysteria.

Their next responsibility was to define technical assistance. Probably the most important function of a state public health agency is the provision of scientifically accurate information to agencies, organizations, and the public in an understandable format and timely manner. Public health programs cannot be based on AIDS hysteria. Yet the amount of misinformation about AIDS has been one of the most difficult issues to deal with during this epidemic. Misguided public policy can almost always be attributed to inaccurate information. A systematic effort is needed to provide timely, technically accurate information in a form that is useful to the

thousands of organizations and agencies in a state.

In Minnesota, we have utilized our local public health system to fill that need. In August of 1987, I outlined responsibilities for community health service agencies which are our local health departments, and suggested that each CHS agency should undertake the following five activities: first, appoint a staff member to monitor HIV-related activities and information; second, convene a local HIV task force; third, provide their communities with accurate information; fourth, develop AIDS-related policies applicable to their areas; and fifth, assess local services resources. To assist in implementing these suggested activities, the Minnesota Department of Health has worked with a subcommittee of CHS agencies to futher clarify the role of local government. In addition, the Department provided specialized training to CHS agencies through four statewide HIV-related conferences and through district level meetings of the appointed HIV resource persons. I might mention that it's our intention to continue to have at least one of those formal conferences per year to keep people updated and to take care of the turnover that is going on in the local public health agencies; and of course, to provide individuals with general assistance as needed.

Based on the assistance that I have just described, the following will illustrate how CHS agencies have responded to the HIV epidemic in Minnesota. The information I am about to quote

comes from two surveys completed by these agencies, one in early 1987 and a second one in early 1989. In 1987, 9 percent of our local health agencies had provided services to a person with AIDS compared to 49 percent in 1989. In January 1987, there were three community-based HIV task forces. Two years later there were 64 task forces with a total membership of 676. In 1987, approximately 60 percent reported that in a typical month they received inquiries related to AIDS. In 1989, 100 percent said they received AIDS-related inquiries in a typical month. In 1987, 52 percent reported providing AIDS-related education programs in a six-month period, compared to 99 percent in 1989. In 1987, 40 percent of the agencies reported having a policy for care of patients with communicable diseases. In 1989, 85 percent had completed such policies, with another 10 percent in the process of developing a policy at the time of the survey. As you can see by these significant increases in service provisions over time, CHS agencies have been challenged by the HIV epidemic and have responded to that challenge in positive ways.

The partnership between the Minnesota Department of Health and the Community Health Services system has provided a forum for sharing resources and talents, both with other CHS agencies and the Minnesota Department of Health. Of course, listening to the discussions today I thought of another area of responsibility that I think the state has probably along with

the federal government and the local level of government. I think it's important that we should be speaking out on actions about others, particularly when there are other governmental agencies which are actually not based on scientific fact and when they're involved in practices or policies which are detrimental to the understanding of what we're attempting to do.

And I speak particularly -- Diane will remember this -- that we had a gentleman come into our country from Holland, arrived in Minneapolis, and was denied continuing transportation on to San Francisco to participate in an educational program there simply because he had admitted that he had contracted AIDS. He had some medicine in his suitcase which brought this to light. He instead was put in prison by the immigration officials and detained here for a week before we were able to get him moved on. This was because of the interpretation of the federal policy, and that policy now at the federal level hopefully is in the process of being changed; but it was very important that we spoke out loudly about that particular situation. We've also had to get involved with our local police department when they have picked up a prostitute with an HIV infection and proceeded then to abuse the confidentiality of that individual. So when those kinds of things happen, I think it's extremely important that the state health department in particular speak up in contradiction to those kinds of practices.

The final area I wish to discuss comes back to the challenges all of us face in developing and providing AIDS prevention and service programs. The first challenge I cited was that of incorporating flexibility and varying levels of response to the HIV epidemic based on the need as determined by local surveillance data.

It is vital that each state provide a base level of HIV information and prevention activities. Certain areas within each state will need a greater level of support and effort. It is an ongoing challenge for the states and the federal government to provide the funding, technical assistance, and continued guidance for those areas that will be hit hardest by the HIV epidemic. It is important that states are able to count on a base level of support from the federal government to implement targeted prevention activities, while maintaining the flexibility to develop programs that are sensitive, and thus more effective, for their particular areas.

A second challenge for this commission is the need to balance prevention activities with support for services. Services planning efforts, such as those currently funded by HRSA, are an important incentive for states to consider the service needs of their infected citizens. Ongoing funding to support these planning efforts is vital to the coordinated and effective delivery of services. It is important, however, not to lose sight of the need for ongoing prevention programs while

developing services.

States have already had to shift an increasing proportion of their state funds from prevention efforts to patient care. In fiscal year 1989, patient care and support services will comprise more than 38 percent of all states-only funds for AIDS programs, doubling the percentages spent on these activities in fiscal year 1986. These are really two distinct needs that are present throughout the nation and should be considered somewhat independently of each other. Without thoughtful, deliberative planning, it will be impossible to respond to persons with HIV infection at their level of need.

I appreciate the opportunity to address this group and to provide some examples of how Minnesota is responding to the HIV epidemic. I am proud of the way Minnesota's public health system, foundations, corporation, legislature, and communities have responded to the HIV epidemic. The programs we have developed here reflect the type of support appropriate to our communities. I encourage this Commission to recognize the need for ongoing flexibility and support for HIV prevention and services and prevention activities. Thank you.

MS. AHRENS: Thank you for your leadership. We're so glad you have been where you are during the growth of this epidemic and I think as a local elected official in this state that I have appreciated so much the willingness and openness of the State Department of Health to include those of

us at the local level that have to deal with this issue, and to give us the flexibility to deal with after we set some clear standards and goals for it I think we can do the job and appreciate that freedom you have given us to move ahead. I think the best evidence of the kind of leadership provided in the state level is in your documentation of the 1987 -- what was going on in 1987 and then what was going on in 1988. It makes it very evident that people were heeding the call from the state health department.

MS. ASHTON: It was very impressive to us at the State level to see how rapidly the counties and cities responded also. Without any additional funding for us, almost everyone of our counties identified a person to be an HIV resource person. We were later unable to give them some additional funding to support that individual but when we initially asked you to do that that was not possible and yet they did go ahead and make that commitment and that meant a great deal to us at the state level too.

MS. AHRENS: I think that we are not uncharacteristic of the other states throughout the country. I know many of those counties as you do out in Greater Minnesota and there is a lot of resistance and conservatism out there, but when they were given the challenge they did respond. They did respond in their own way but it's normally a positive response and I think your report has given us a sense of that. Are there

any questions?

DR. KONIGSBERG: I would just like to add my congratulations on the accommodation of the relationship with your local health department. I think that's real critical and that doesn't occur in every state. I like the way that you work.

MS. ASHTON: One thing that I should mention, Charles, is that this networking didn't happen because of AIDS. The networking had already been established. Fortunately, it's a network that has been in place for the last 10 or 12 years, but it certainly is a wonderful way to be able to keep in communication and to work with our local public health officials.

MS. AHRENS: Thank you and we look forward to your participation tomorrow.

Mr. James Bulger is here and he is with the New York State AIDS Institute. We welcome you.

MR. BULGER: Good afternoon, and late in the afternoon it is. Before I actually read my prepared testimony, and I believe you all have a copy of it, I would also like to commend the commission in general and in particular this work group on what you're doing. I think from all of my travels and personally by telephone with several of my colleagues around the country there is indeed a need for federal government, state governments, local governments in the private sector of

community-based organizations of business, industry and so forth to plan and develop policies together. Hopefully out of your efforts today and as the commission moves along we'll see some direct federal involvement in that and a better sense from the federal government as to how states should react and act. I've also --no one has said anything about the staff yet and so I will. I have met some of the staff. They came up to New York about a month and a half ago and I will say that my perspective, Maureen, Joan and Jane are exceptional people and I can tell you that Dr. David Rogers has told me around the states so you are well served by your staff as well. Now that I have gotten my brownie points in with the staff.

Commissioners, Committee Staff and Invited Guests, my name is James T. Bulger and I am the Deputy Director for Governmental Relations and Strategic Planning in the New York State AIDS Institute which is a component of the State Health Department. It is indeed a pleasure and an honor to have this opportunity to describe a number of activities and models of governmental coordination employed in New York State with the HIV and AIDS epidemic.

Specifically, I would like to describe the role and responsibilities of the New York State Department of Health AIDS Institute and mechanisms that we employ in New York State for coordinating the various agencies of state government to combat the epidemic. I would like to describe a regionally-based HIV

strategic planning process that will assure local input into state planning and policy development. I would like to describe the AIDS Institute congressional and federal agency strategies to both broaden the federal financial commitment nationally to HIV and AIDS and perhaps in a more immediate way, to commit funding to states like New York with a high seroprevalence in case count in a matter of proportion to the burden shared by all the states.

Prior to going into these let me first form a context for my presentation by spending three or four minutes describing what the epidemic is like in New York State. During the past decade, AIDS and other illnesses linked with the human immunodeficiency virus have emerged as a public health crisis affecting New York States residents. AIDS has exacted a heavy toll of illness, suffering and death in the state. Through August 1989 more than 24,000 residents have been stricken with AIDS. The number is really quite a bit higher than that because we have about a 9 or 10 month lag in reporting so in reality it's probably that number is over 30,000, close to 30,000. To date approximately 14,800 individuals have died prematurely from AIDS. AIDS is now the leading cause of death for New York City males ages 30 to 59, and among New York City females ages 1 to 9 and 30 to 39. New York continues to have more reported cases of AIDS than any other state with approximately 23 percent of the U.S. total.

Compared with national statistics New York State has a higher proportion of cases among intravenous drug users, minorities, women and children. The annual incidence of AIDS in the state has risen from fewer than 500 cases in 1982 to nearly 7,000 new cases in 1988. Assuming that our projections of newly reported cases are accurate, more than 700 new cases per month during 1989 will have been confirmed.

Of the AIDS cases reported in New York State, excluding those diagnosed among state prison inmates, 84 percent have occurred in our residents in New York City and 12 percent elsewhere in the state. AIDS cases outside of New York City are closer essentially in the down-state area, Westchester County and Long Island, and also the major population centers upstate, Buffalo, Rochester, Syracuse, Albany. The majority of AIDS cases in New York State have occurred among homosexual/bisexual men and IVDUs, intravenous drug users.

Other affected populations include their heterosexual partners and offspring, and recipients of HIV-infected transfused blood or blood products. Although homosexual/bisexual males still account for the greatest cumulative number of all cases, 11,209, the percent of total cases among the population has dropped to 45.5 percent from a figure of 60 percent prior to 1986. The leveling-off of AIDS incidence may be associated with adoption of risk reduction practices within this group. White males account for 62 percent

of the homosexual and bisexual cases, with 20 percent among blacks and 16 percent among Hispanic men.

New York State consistently has reported a higher proportion of AIDS cases among intravenous drug users than the national average. In New York 42 percent of the total cases are intravenous drug users, compared to less than 28 percent nationally. While recent data suggest a slowing in the rate of increase of new cases among homosexual and bisexual males in New York State, surveillance indicates a dramatic and ominous acceleration in the number of AIDS cases among IVDU's. In 1988, new cases of AIDS diagnosed among IVDU's, 1,928, exceeded for the first time the number of reported homosexual/bisexual cases, at that time 1,670. I might add that that trend will never change, that we're bascially looking at an outrageous epidemic of AIDS and HIV infection among the IV drug using population. The emergence of intraveneous drug use as the predominant risk factor has major implications for the course of the epidemic and for potential spread to heterosexual partners and offspring of drug users.

Although the annual number of AIDS cases attributable to heterosexual contact has increased steadily, less than 4 percent of all cases fall into this risk category. Through August 1989, 782 heterosexually transmitted cases had been reported, 749 then, 96 percent of whom were female sex partners of persons at risk for AIDS.

The percentage of AIDS cases attributable to transmission by blood transfusions or the use of blood products has remained low. Only 245 cases, about 1 percent, have been associated with blood transfusion, and 59 cases, .2 percent have been associated with the use of antihemophilia factor concentrates and other blood products.

Within New York State blacks and Hispanics have borne a disproportionate share of the burden of AIDS. The 8,360 cases among blacks represent 34 percent of all cases to date, even though only 13 percent of the total state population is black. The 6,442 cases identified as Hispanic account for 26 percent of all AIDS cases, while only 10 percent of the total state population is Hispanic. Whites comprise 39 percent of all AIDS cases to date and 75 percent of the total population. In 1988, for the first time during the AIDS epidemic, the number of new cases diagnosed in blacks exceeded new cases in whites. As AIDS has increasingly affected intravenous drug users as well as their heterosexual contacts and offspring, there has been a corresponding increase in the number and proportion of black and Hispanic cases. Blacks and Hispanics comprise 81 percent of all AIDS cases attributable to IV drug use. More than 80 percent of all females with AIDS are black or Hispanic, and 90 percent of all pediatric AIDS cases. Through August 1989, 540 pediatric AIDS cases, those less than 13 years of age, have been reported with 485 -- that's a number I have changed in my text and you

might want to make that change, 485 have been infected perinatally by their mothers, this is by maternal transmission. Following 23 percent -- again another change up from the 18 shown in my testimony -- were infected through contaminated blood products.

Lastly, the total number of reported AIDS cases is projected to increase from the current level of approximately 24,000 to 25,000 to over 90,000 by 1994. And this is by far the tip of the iceberg because projections right now of the number of HIV positive individuals in New York State ranges from 200 to 400,000 individuals.

As you can see from the above, New York State, the epi-center or one of the epi-centers of the HIV/AIDS epidemic nationally has been devastated. In response, Governor Mario Cuomo has mandated a clearly defined strategy to confront the epidemic, entitled, AIDS New York's Response - A 5-Year Interagency Plan. I have given each of you a copy of the plan. I have one right here, we're planning to mail copies out to each of the commission members and other copies to the staff as you need them. If there are individuals in the audience, I'd be happy to take your name and phone number and mail copies out to you as well. I will refer to this document throughout the remainder of my presentation as it is indeed the template used by New York State government to combat the epidemic.

I have already mentioned that I'm going to divide the

rest of the presentation into three or four specific components. The first of which is the role of the AIDS Institute as a model for state government coordination and action. Through legislative mandate, the AIDS Institute was established within the state department of health in 1983 to coordinate New York's response to this emerging health crisis. State funds for the work of the institute have grown from $5.2 million dollars in 1983 to more than $45 million dollars in 1989. Under its mandate to advocate for and implement State HIV/AIDS initiatives, the institute has sought to focus and integrate state agency activities and to serve as the nexus for the overall statewide total response to the epidemic. Since 1983, the role and responsibilities of the AIDS Institute have expanded dramatically. Initially a department of health unit focused on education/prevention and sound patient support services. The institute has emerged by 1989 as the principal organization in New York State government with the responsibility for carrying out and/or coordinating all state sponsored HIV/AIDS activities and services.

In addition to the $45 million dollars in state funds, the institute has approximately $37 million dollars in federal government and private foundation funding, bringing its total annual budget to $82 million dollars. In total New York State government contributes $204 million dollars to all state agencies for the HIV and AIDS epidemic. The institute utilizes

the $82 million dollars to conduct a wide range of programmatic initiatives, either directly or through contractual arrangements. Direct services include an extensive agenda of education and training; HIV anonymous counseling and testing through 50 state-operated clinic sites; health care and human services program and policy development, including: Medicaid rate enhancements for acute, long-term care, home care and primary care services; the provision of AZT and other approved drugs through the state AIDS Drug Assistance Program; and governmental relations and strategic HIV planning services.

With respect to contract services, the AIDS Institute provides financial support to approximately 300 community-based organization; health, substance abuse and human service providers; academic institutions and other miscellaneous contractors. These contractors provide the state with a wide range of services including: training, confidential counseling and testing, community-based services including: psycho-social support, case management, legal support, housing, health care and other related human services directed to the general public, targeted high risk population groups and people with HIV/AIDS.

In its dealings with community-based organizations and health care providers, the AIDS Institute has adopted a partnership position. Decisions and policy questions that impact on major statewide initiatives are discussed thoroughly by a number of external policy advisory committees. For

example, in carrying out its mandate to develop and expand the AIDS designated care center concept, the 17 designated care hospitals in New York State participated in policy development through an elaborate committee structure. Essentially, the 17 hospitals participate with the AIDS Institute in a true spirit of partnership. This is but one example of several that I could name in which we do interact very positively with community providers and activist groups.

The next category is how in New York State we coordinate the involvement of the 24 state agencies that have a role in the HIV/AIDS epidemic. Given the enormous undertaking of addressing the HIV/AIDS epidemic in New York, the need to coordinate and stimulate the actions of 24 state agencies is essential. A model has been developed in which the Deputy Secretary to the Governor for Human Services and the AIDS Institute collaborate closely to assure that each agency has an active and effective strategy that results in successful implementation of program goals and objectives. The important point is to get the governor on your side and to get the govenor right in the middle of the foray. That makes it much more clear and interesting and no doubt easier for the department of health to have any coordination control over the other state agencies.

There are four major components of the model, namely: the Governor's Interagency Task Force on AIDS, the AIDS Five-Year Plan which I have mentioned already, Oversight by the New York

State AIDS Advisory Council and Memoranda of Understanding between individual state agencies and the AIDS Institute. All of this comprises the full model that I think we're beginning to see some real benefit out of.

The Governor's Interagency Task Force on AIDS functions as an interagency advisory body to review relevant issues and to develop recommendations on major policy matters. The task force is comprised of high level representatives from each agency in state government with direct involvement in the HIV epidemic. It is chaired by the Deputy Secretary to the Governor for Human Services and staffed by the AIDS Institute. There is an attachment to the presentation that lists the 24 state agencies that I am making reference to now. Subcommittees of the task force, for example: housing, prevention, criminal justice, strategic planning and HIV positive mentally ill chemical abusers work to identify problems and issues that cross agency boundaries and promote interagency cooperation. It meets monthly, following an agenda developed jointly by the governor's deputy secretary and institute leadership.

Through the Interagency Task Force the 24 state government agencies are provided with overall policy guidance; coordinate programs closely with each other to minimize duplication of effort and fragmentation; they gain a clearer understanding of the role of all agencies and they contribute to a structured, yet sensitive statewide response to the epidemic.

The second component, the five-year plan, was developed through an intensive and searching process during 1988 involving consultation with more then 300 key individuals and cooperative planning among numerous state agencies which participate in health and human service delivery including care of institutionalized populations at risk. The AIDS Institute coordinated plan development and identified and focused attention on major HIV and AIDS issues and needs. In this process, the institute sought recommendations from individuals and groups statewide representing health and social service providers, substance abuse agencies, local government, high risk populations, public employee unions, community service organizations, business interests, the criminal justice system and people with HIV infection and AIDS. A series of ten roundtables were developed and planned and held bringing together participants from all these backgrounds around several issues including minorities, women, children, adolescents, the gay community, HIV drug users, prison inmates, housing, AIDS in the workplace, and upstate New York issues as compared to New York City issues. We always have to keep in mind that there is an upstate New York when we talk about HIV and AIDS. The plan contains more than 200 specific recommendations that together constitute a New York State strategy for halting the spread of HIV infection within the populace, a commitment to caring for those who are infected, and an ongoing effort to prevent

discrimination against individuals and groups at risk for AIDS.

As previously mentioned, the Plan provides state government with a strategic template for action. It will be updated every 18-24 months to assure that the recommendations are current, and comprehensive. Through the efforts of the interagency task force, the plan's recommendations are continuously reviewed and monitored to assure timely implementation. The five task force sub-committees named above have responsibility for ongoing evaluation of all recommendations and reporting back to the governor's office and also to the AIDS Institute on successes, problems, funding deficiencies and other barriers to implementation.

In addition, the progress of implementing the plan is monitored and evaluated semi-annually by the New York State AIDS Advisory Council which is also staffed by the AIDS Institute. The advisory council is a 13-member body created through legislation in 1983 to coordinate public and private efforts in the fight against HIV and AIDS. The membership includes recognized leaders from the public and private sectors nominated by the legislature and the governor to assist state government to gain an understanding of complex and controversial issues and to recommend appropriate action. The chairman of the New York State AIDS Advisory Council, Dr. David Rogers, is also the distinguished co-chairperson of the National Commission on AIDS.

The first AIDS advisory council status report on the AIDS

five-year plan was completed in November of 1989. It provided an objective and impartial review of each agency's contributions to the successful implementatin of the plan. This process of external review will continue on a semi-annual basis through the life of the plan and its future updates. The impact of the objective review process is enhanced through periodic discussions between Dr. Rogers, the governor and the state commissioner of health on issues of concern and importance.

The last component of the model involves annual memoranda of understanding between key state agencies and the AIDS Institute. The purpose of the MOU's is to codify mutually agreed upon objectives for the forthcoming year and to specify initiatives for inclusion in the agency's next state budget request. To date, the AIDS Institute has finalized ten memoranda of understandings. In total we expect that number to reach 15 or more. We also have an attachment that indicates the agencies in which we have affected and will affect MOU's.

The HIV Regional Plan is the last major component with respect to the coordination process.

MS. AHRENS: I wonder if I could stop you for just a moment. I know that because you come from New York that there is so much going on there and we want to ask you some questions and I'm afraid that time will be taken. Could you, in a minute or two summarize the last two sections of your paper so that we can have some time for questions?

MR. BULGER: Certainly. An old secretary of mine once said, "Jim, you talk more than anybody I know and say less," and once again I've done that.

MS. AHRENS: That's not true.

MR. BULGER: Let me spend probably one minute describing the Regional Planning Process which involves the eight state health systems and agencies that are quasi-public organizations funded primarily by state government to conduct health-related human services planning and policy development at the local level. The State's AID Institute has contracted with the AIDS organizations, they in turn have developed eight coalitions, actually more than eight coalitions, throughout the state that are comprised of health providers; substance abuse providers; criminal justice organizations; advocates; community-based providers and so forth to assist the state in updating its five-year plan. By a contract they will send to us to update a regional update to our five-year plan, will integrate the eight regional components reaching each of our periodic updates for the state's five-year plan.

The last component is our involvement with the federal government. It's an activity that we took on only over the last year or so. We meet almost monthly with our New York delegation in Washington and with other individuals and staff people from both sides, the House and the Senate, to discuss a variety of issues. Our bottom line is to increase the inaggregate, the

total number of dollars available on the federal level for HIV and AIDS programs nationally; and also as I mentioned earlier, to stress the need for proportionate funding because we in New York State with 23 percent of the cumulative incidence are finding that we're being shortchanged by the federal government on a percentage of total basis and we're working very hard with our New York delegation and others to try to work really into future legislation that may involve formula approaches, may involve live AIDS -- live individuals who are alive with AIDS in each state as a proxy for a need with respect to service delivery funding.

I would be happy to discuss any and all of this with you and I'm sure we'll have that opportunity tomorrow. Sorry it took me so long to get through the first part of that.

MS. AHRENS: I think we would like to know how the state interacts with New York City and its five boroughs?

MR. BULGER: The state health department has a very close collaborative relationship with the city health department, that's number one. Even though we have already in the newspaper indicated that the two health commissioners don't talk to each other, and indeed they really don't, but on a staff-to-staff basis we talk to each other very pleasantly, all the time. As a matter of fact the CDC Prevention Grant to the City of New York and to the State of New York, two separate

grants, instead of a competition in mind the city and the state got together before the applications were mailed out so that we could be relatively similar with mutual exclusive inititives and then once those grants were awarded we got together to make sure they were well coordinated. We worked through the Jefferson AIDS Consortium, along with the HRSA Demonstration Programs and RWJ Demonstration Programs. I'm the principal investigator of both of those grants to ensure that the five boroughs of New York City have a relatively integrated process through AIDS and the health system's agency as well and also our state and community service programs to make sure that the providers in the other organizations in each of the boroughs and the politicians from the boroughs have access into state and city level planning over HIV and AIDS.

And we work -- also we have 300 contracts with providers and community agencies, I guess I mentioned those. So we have a very close working relationship with most of our own attorneys in New York City. You know this is a panacea, everything and anything that I say is a panacea because the disease is raging in New York City and elsewhere in New York and we have yet to come up with the secret on how to deal with it from an organizational point of view and certainly from a service delivery point of view.

MR. AHRENS: Charles, did you have a question?

DR. KONIGSBERG: Some of us live in states that have seen the demise of organized health planning as they don't have HSA's anymore or any organized health plan at all at the local and regional level. How valuable have you found the HSA's to be in the overall process, and I guess a little detail in the limited time we have as to have they been particularly helpful?

MR. BULGER: The HSA's run a wide range. Some are very good, some have yet to become very good. The good ones have spent about -- the best ones have spent two years working with local coalitions putting plans together. These are multi-county HSA's, and they have put together HIV/AIDS plans. These are functional coalitions that have been in existence for about 16 years. They have sent us their plans, we have used their plans building our plan already. Five of the HSA's have not done this and through these contracts we're going to bring those HSA's up to a point where we are dealing with them. I think the potential is far greater than the reality so far. I think they're well intentioned, they're not staffed as well as we'd like them to that's why we've contracted with them so that they can hire staff, but they seem very interested and I think it's going to work. But right now -- if I came back in a year I think I could tell you that it is working not that I think it's going to work. We're still relatively new in infancy right now.

MR. KESSLER: I have two questions. They're

not exactly related to that, although they may be related. The first is what are you doing to prepare your legislature to keep pace with your projected numbers, and have they done that to date in terms of your --

MR. BULGER: No. Clearly, the government, the legislature, anyone who has any power at all to commit funding in New York State to address this problem hasn't come nearly close enough to being able to really address the problem. We're way behind the AIDS epidemic and every day, I dare say every hour not to become overly dramatic, we're falling further and further behind.

We do have a very close working relationship with our legislature, especially the downstate democrat liberal assembly within the legislature and after the governor approves the budget and yesterday -- last night I had to come to Minnesota to watch Mario Cuomo give his state message on TV, but after the govenor approves a budget it then goes to the legislature and every year over the last four years the legislature has voted to that budget in terms of HIV and AIDS. The $204 million dollars committed to state government in New York could be tripled, it could be tripled, and based on our projections it should be tripled for us to have any chance at all with the service delivery system together, especially in New York City. So the answer is "no" they haven't, but given the constraints of a very, very large deficiency in New York State, a deficient in

New York State they're doing what they can and I'm trying to stand behind them in that response.

MR. KESSLER: The second question relates to the issue of burnout. I think your plan looks marvelous on paper and in many sections of the state it works real well, but in some sections it apparently is near collapse because the staffs seem to be overwhelmed, seem to be swamped in paperwork responding to the various forms from the department of health, and from perspective seem to be moving on leaving vacuums. And I'm wondering if you're aware of that and if you are how you're addressing that in terms of a future planning issue because it seems that you're not going to have enough people to staff programs, you're going to continue to burn people out?

MR. BULGER: Like any good government agency we require our contractors to fill out documents with numbers and case counts and so forth. We have to do that. We try to minimize it although I'm sure when one speaks to the providers that we contract with, the amount of paperwork is not out of bounds.

The burnout factor is real but it's really -- there are two factors that work here, one is the fact that there are so few people, especially in New York City in the health care delivery system relative to the need for staff in the health care delivery system, that we can't fill the vacancies that have been vacant for a long time. For example, in hospitals and in

other health care provider categories and in keeping the best agencies. Then the other issue is the one that has already been mentioned, the burnout factor. We work very closely through our staff with the community-based agencies. We find that in our own staff we have a burnout factor. Dealing with this issue seems to be a 12-to-14 hour a day, 6-to-7 day a week effort on the part of many people and they burnout frequently.

We have funding in the state in the agents that you budget but we contract with providers for support and other forms of support for the providers with respect to maintaining their own sanity in the community. But by and large we're finding that we're fighting a battle on both a regular basis but also a battle in which we're loosing in small increments in terms of keeping people in their jobs, good people, people who have been around for a long time, keeping them in their jobs and also bringing new people into the health care delivery service.

MR. KESSLER: So in other words, the problem is as human resources is becoming less critical the issue is cash?

MR. BULGER: I think in New York State human resources is the number one problem that we confront in terms of the epidemic. We hear -- there aren't words to describe this. A hospital in New York City last week, Bellevue Hospital, in other words that primarily is filled with people with AIDS, they have a competent of 32 nursing positions and 8 of those

positions are filled. And that is the story that we hear not infrequently around the City of New York. It's less a problem upstate, but it's critical in New York.

MS. AHRENS: I want to thank you very much and we look forward to your participation with us tomorrow.

MR. BULGER: Okay. Thank you.

MS. AHRENS: Tim Wolfred is here from the San Fransisco Mayor's HIV Task Force. We welcome you. Sorry about the late hour, but --

DR. WOLFRED: That's no problem. Thank you. Commissioners, Director Byrnes, Friends, it is late and I will try not to repeat too much of what has already been said.

I come with ideas from the mayor's task force in San Fransisco but I'm also speaking from my perspective as being a former executive director of the San Fransisco AIDS Foundation for four years, I sit on the board of the National AIDS Network which Commissioner Kessler and I and others founded a few years back, and the Board of the AIDS Action Council which is located in Washington D.C.

I must say in all of this work my primary perspective is as a community psychologist. My training is in community psychology and community interventions and to impose in my strong belief and my experience that in taking on the social and health crisis, that the government is best to help people do it for themselves and that particularly applies, I think, to AIDS.

Rather than doing things to people or for people but rather we empower them to take care of themselves and we help them out much more in taking that kind of approach. I think that's been my advice in all of my AIDS work. I'm not going to read my text, I just want to digress and focus on some points about the role of local government which is what you asked me to do in your letter of invitation. Normally I would take this opportunity to beat up on the federal government as I have in other sessions, but I'll try to stay focused on the local level.

I think the first and biggest responsibility and obviously the starting point is strategic planning. The local level part of the local government must start out with a strategic plan about how they're going to address the AIDS epidemic in their community and that picture is going to look different to every community based on demographics, pre-existing service systems, the availability of nongovernmental support and such. So in that plan the government, the health department will lay out the needs, talk about what responses need to be made for those needs and then be energetic about getting those things in place, implementing the programming around those responses.

I have had a lot of experience in San Fransisco, I've also had some experience in Seattle and Los Angeles and I think it's real clear where the health department takes a strong central role, a coordinating role, things go much better. Los

Angeles being an example of where they have avoided that role until more recently when things are much more contentious and slow to get going. Seattle and San Fransisco being good examples where the health department did take a good role and I think the systems reflect it.

I was particularly impressed by a program in Seattle I visited recently that the health department helped to generate in which they plugged together three very different agencies: a gay male substance abuse agency, Indian Health Board of Seattle, and a street youth agency to develop programming, prevention work with substance abusers, among those populations. The result is a lot of skill sharing among those groups and they got funded by the Robert Wood Johnson Foundation for that project because they were so well coordinated. The health department made that happen and when the health department doesn't take that role it doesn't happen. You see fighting among those groups rather than cooperation and skill sharing.

It's important that the health department in all of its planning and setting up programs include the impacted populations. You have to have women, you have to have gay men, you have to have the minorities impacted on the staff of a health department, on your advisory committees, and in the staffs of the agencies when you take on the problems.

More specifically I want to talk about three areas: one being prevention then which is going to be obviously part of the

strategic plan and just three points on that. A lot of what I'm going to say assumes that what's been said earlier today has been said. It's important that the local government, I think, fund the prevention work that the federal and state governments will not fund. There are so many prohibitions wrapped around the money as we know. In the state of California as late as last year, in 1988, the words condom, anal sex, and bleach were prohibited in any kind of materials funded by our state government. It's pretty ridiculous and obviously the governor was not on our side in this situation and he has not been in California very often. So it's up to the local groups to fund raise and find some way of getting that money to pay for materials that are essential for prevention work.

The second issue is around gay men and we want prevention work to go around to all populations but often governmental agencies shy away from, I think, funding for gay men. We heard the examples from Texas from Lori Palmer. But I think it's been my experience, it's been more the rule than the exception for that kind of blame to avoid in any way so you're not promoting a gay life style in the various funding sources. When I first saw the organizational chart for the Center for Disease Control AIDS Prevention Program and they started to get it together in 1987, they had boxes on their for outreach to minorities, for women and children's issues, for incarcerated populations, for health care workers, and then they had a box called special

populations. That's where gay men were because they couldn't use the word.

I think a lot of the funding you see here from government bodies tends again to not go in that direction. It needs to hit all the populations and in much greater dollars, obviously. It's not over with the gay male population as we sometimes fear, even in San Fransisco. There is relapse and if you don't keep it up, keep up the drum beat of say sex and protected sex we're going to see the infection rate going back up. It was cited recently to move money out of prevention into health care and obviously that's very shortsighted and I hope you will speak against that. We have a health care crisis now in some localities because we didn't do prevention work earlier. If we stop doing it now, we're going to have an even bigger health care crisis later.

Another area that we'll probably need to take up because other arms of government condone it is anti-discrimination laws. Those laws need to be in place to take out the fear and the bigotry and engage other populations in what we're trying to do work on and help them do for themselves.

The last thing that we're going to help the government to do is go begging for money to do all the things that they said they want to do in their strategic plan. In San Fransisco, our health department two years ago projected our health care budget in public and private dollars as approaching $300 million

dollars in 1993, and that's compared to $69 million dollars in 1988. And we've since added another $65-to-$100 million dollars for early intervention work that we think is obviously critical in terms of preventing progression of disease. So we're talking about a possible gain of $400 million dollars in three years in San Fransisco. That's something the local government is obviously not going to be able to fund.

And so the mayor a year ago created his HIV Task Force in San Fransisco to take on some of these emerging issues in the epidemic and it includes the corporate sector and the private sector in health care as well as the public sector and educators and religious leaders. One of the first things we've taken off on in that task force is going after money. The blueprint is there of what needs to be done but the money is not there for the blueprint to expand and keep up with need. But what if other corporations, Chevron, Bank of America, the Urbans to make sure that they're including in their insurance policies coverage for pro-health care, for early intervention of AZT, aerosol pentamidine, and with a few corporations leading that effort it's much easier to bring the other corporation along.

And because we have a plan coming out of our HIV Task Force with public and private partnership we see each segment that are willing to do their piece when they see the other segments are going to be doing theirs and it's been very important that our local level take a leadership role and keep

forming these partnerships so that all the partners come into place.

We're going after private foundation money to fund various parts of the plan. And obviously we're going to need lobbying at the federal and state levels for the dollars that are going to be necessary to keep us from going broke.

I would just conclude by saying, repeating I guess in this area what others have said and that's the need for moral leadership from our government. When that leadership isn't there, things are much more difficult at the local level and I talk about the fact that in the community agencies and the community groups we have too often turned to anger, to begging, to radical activism because that leadership has not been there at the time. Our healing energies get diverted to these other more unpleasant duties that we have to take on because the federal government is not taking it on.

I was struck recently by a comment coming out after the earthquake in San Fransisco. The Bay Bridge reopened 30 days after the earthquake and the chief engineer, the man that was in charge of getting it repaired fast, how he did it so quickly. It was really a major piece of engineering work. And he said that he had been told by his boss, the Chief of the Transportation Department in California, to do whatever it takes to get that bridge fixed, spend whatever amount of money he needed to spend to get that bridge fixed, it's a vital economic

link from the Bay area, and he did it. And from my perspective, AIDS is just as fixable as that bridge and we need leaders who will say the same thing about AIDS. We're going to do whatever it takes to get this virus stopped and to stop the dying. Until we have that leadership, we're going to have that much more activity on the local level channeling diverted as I said into the activism.

A final contingent to that is when the government can't lead, I think it's very important for the government to get out of the way. We have a lot of examples of that. In San Fransisco, -- under California law, for instance, it's illegal to dispense syringes without a prescription. But we have a group in San Fransisco that's been operating for a year, Prevention Point, street workers that came together ad hoc to do a needle exchange program and the city officials have agreed to look the other way, the police department, the mayor's office, as they go about trading clean needles for dirty needles, and they have at this point up to 10,000 needles a month that they're distributing on the streets of San Fransisco in the areas where there's still a high concentration of needle users. It's been very important that our government get out of the way in that activity.

I think that kind of concludes the big things I wanted to touch on and I thank you.

MS. AHRENS: Larry, did you have a question?

MR. KESSLER: Tim, you mentioned the $65-$100 million dollars for early intervention. That's your plan, but at this point you don't have any funds for it; is that correct?

DR. WOLFRED: Right. The original plan outlined $100 million dollars worth of health services for intervention. That includes the doctors, the nurses, the testing, the drugs. About $35 million of that is in place right now but in the existing systems, but to pull it out we need another $65 million dollars.

MR. KESSLER: Where did that initial $35 million dollars come from?

DR. WOLFRED: It's a mix of city and state. Part of it is the ARMS testing sites that are funded largely by federal dollars, part of it is the existing city clinics which now do some monitoring of HIV positive and they encourage you come in for 6 month checkups. But we have -- it is estimated up to 30,000 people HIV positive in San Fransisco and only a small portion of those are really in the health care system right now in an early intervention sense. And to get them all in and to have the services available, it's going to take that much more money. The federal money, the city providing, is also leaning on the private hospitals to do a piece of it as well. The further money about the budget I talked about is both private and public dollars and it includes health care programs, hospitals, and clinics.

MR. KESSLER: Do you know how much of the $400 million dollars is now federal?

DR. WOLDRED: No, I don't. I could get those figures. Those figures are going to be updated this spring by other departments as well. Those are projections made in 1988 and they may look somewhat different and certainly the epidemic looks different now with AZT and the other drugs.

MS. AHRENS: Tim, could you possible tell us in about two minutes what we should say to the federal government?

DR. WOLFRED: Well, one is reform the health care system, get it to where it needs to be now, not only to take care of people with AIDS but many other health care needs that face us and that means putting emphasis on health care which is costly, getting into prevention activities. And secondly, I think, get money particularly in AIDS to the community-based groups. Right now we're getting money from CDC to agents like HMH (ph.) which is actually putting Boston on the map, it's quite an anarchuous process. I think the best work in many of these areas goes on with the community groups and I think the federal government in anything you're talking about they say, "Well, it's too difficult, we can't do that, it's complicated and we can't trust." I think if they put their heads to it they could come up with a system that is streamlined, opened up, and got the money down to where it use

to be in order to get the work done in a much less expensive way too in terms of how it gets spent. I think those two points.

MS. AHRENS: Well, it has been a long day but I thought that your analogy with the bridge and the earthquake is very germaine to what we're doing here and I thank you for that. Thank you and we'll see you tomorrow.

DR. WOLFRED: Good. Thank you.

MS. AHRENS: This will conclude this first day of work of the sub-working group and I thank all of the participants who have remained with us. Some of you we'll see tomorrow and have a nice evening.

(WHEREUPON, the first day of proceedings were concluded.)

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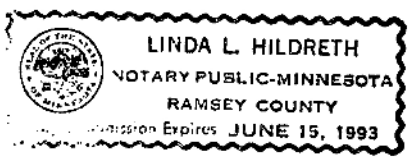
REPORTER'S CERTIFICATE

I, Linda L. Hildreth, a court reporter, do hereby certify that the foregoing transcript, consisting of pages 1 through 210, is a true and accurate record of the proceedings to the aforementioned matter to the best of my ability.



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Dated this 20th day
of January, 1990.